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THE SPINAL CORD INJURED AND SPOUSE:
A CASE STUDY OF ROLE CHANGE AND DYADIC ADJUSTMENT

by



ELDONNA SHARON GAIL BRINTNELL

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research, for acceptance, a thesis entitled The Spinal Cord Injured and Spouse: A Case Study of Role Change and Dyadic Adjustment submitted by Eldonna Sharon Gail Brintnell in partial fulfilment of the requirements for the Degree of Master of Science in Family Studies.

DEDICATION

To Mary Olga and Pauline who established the pace, the expectations and provided the ultimate model. Their drive and accomplishments have served as my standard.

ABSTRACT

Though the study of the impact of a spinal cord injury has become more prevalent in the last decade, very little research has been undertaken to increase the understanding of such an event on the marital dyad. Few researchers have included the spouse's appraisal of the marital relationship, thereby seriously limiting the scope of their study.

This research was designed to explore the impact of the husbands' traumatic spinal cord injury on the functioning of the marital dyad and to identify the dyadic change process that was precipitated. A case study method was selected to facilitate in depth exploration of changes in the marital dyad and to determine the husband's and the wife's present role functions as breadwinner, as social companion and as sexual partner.

The data analysis of two marital dyads revealed an adjustment process which can be differentiated into three stages: Assault, Upheaval and Recovery.

The final step in the recovery stage was the dyads' decision to accept or reject the new dyadic roles that had emerged as a result of the process. The findings indicated that Dyad A rejected the new roles and ultimately chose dissolution of the dyad while Dyad B accepted the new roles and continued the marital relationship.

The findings were presented using the symbolic interaction conceptual framework for interpretation and discussion. Implications for further dyadic research are presented as well as some considerations for health care professionals.

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CHAPTER I

INTRODUCTION

The psychosocial adjustment of the disabled has become a topic of review during the last decade. Concern for the clients' optimal post-injury rehabilitation and adjustment has expanded beyond the limitation of their physical status to encompass the effects of psychological and social factors on their expected adjustment to the permanent change in their life situation (Lawson, 1978; Roesler & Bolton, 1978).

Though the psychosocial literature dealing with the disabled has become more prolific, it has focused primarily on the individual's response to injury. To date minimal research has been conducted on the effects of disability on the role functions of the marital dyad. It has been said that the husband-wife relationship is the center of family life especially with reductions in actual family size and kin networks (Fink, Skipper & Hallenbeck, 1968). Therefore when the husband sustains a severe permanently disabling spinal cord injury, there will be a disruption in the role function normally associated with being a husband (Marra & Novis, 1959; Nagi & Clark, 1964; Christopherson, 1968; Kahn, 1969; Harris, Patal, Greer & Naughton, 1973). This will demand a major reorganizing of assigned roles and adjustment to the new situation. A permanent disability may preclude the husband from returning to the same

job or work at all, participating in recreational and social activities and being independent in sexual functioning.

Purpose of the Study

There will be a major disruption of marital roles following the husband's spinal cord injury which in some instances may even preclude the return of normal functioning in specific roles. This study focused on the spinal cord injured (SCI) male and his spouse.¹ Thus the purpose of this study is to explore the impact of disability on the functioning of the marital dyad and to identify the dyadic process of change that is required by a spinal cord injury. It is hoped by increasing the understanding of the process that couples go through in attempting to restabilize their relationship that this would assist health care professionals in dealing more effectively with the unique problems of this particular dyad.

Statement of the Problem

The general objectives for the current study of the SCI marital dyad were to explore the changes in marital role behavior of the couple as a result of the husband's permanent disability. The specific research objectives were derived from studies on marital role behavior and disability (Marra & Novis, 1959; Deutsch & Goldston, 1960; Klein, Dean & Bogdonoff, 1967; Fink et al., 1968; Gibson & Ludwig, 1968; Stone &

¹ Spouse in this research, always refers to the wife.

Shapiro, 1968; Collette, 1969; Ludwig & Collette, 1969; Sadoughi, Leshner & Fine, 1971; Carpenter, 1974; Peterson, 1979), from the work of the proponents of symbolic interactionism and role theory (Mangus, 1957; Gordon, 1966; Burr, 1973) and specifically the work of Crewe, Athelstan and Krumberger (1979).

This exploratory study attempted to discover some answers to the following general questions. As a result of a husband's permanent disability:

1. What kinds of changes occurred in the marital role functions since the husband's disability?
2. What is the nature of the process, post-injury that brought about these changes?
3. What was the couples' current level of acceptance of the functions of certain roles such as breadwinner, social companion and sexual partner?
4. What was the couples' current appraisal of the dyad's general functioning level?

The case study method was chosen for this research as it provides an effective means to gain insight into the dynamics of people's behavior when a significant turning point or event has necessitated change (Wisemann and Aron, 1970).

Limitations of the Study

The following are considered to be limitations in this research:

1. The amount of time and effort spent in data collection may not be equally returned in the form of illuminating results.

2. The results of the study must be confined and not generalized to a larger, similar population.
3. The data collected are retrospective and subject to faulty recall and to the desire on the part of the subject to comply.

It was with the full awareness of these limitations that the decision to use the case study was made. It was thought that the strengths of the approach, which will be discussed in Chapter VI, Methodology, far outweighed the noted disadvantages.

Terms and Definitions

The following terms were selected for definition as they are key terms in the text of the thesis. Dorland's Illustrated Medical Dictionary was used as the primary reference (1974). For a more comprehensive list the reader is directed to the glossary of terms in Appendix E.

Paraplegia	paralysis of legs and lower parts of the body.
Quadriplegia	paralysis of all four limbs.
Reflex Arc	total pathway of afferent nerves by which impulses initiated in stimulated receptors reach gray matter of spinal cord; after synaptic transmission within cord, impulses leave by afferent nerves which transmit them to appropriate muscles.
Phantom Orgasm	the subjective experience of an orgasm in the absence of a physiological response.
Functional Loss	inability to use a body part for its prescribed application to living.

Summary

Much has been written about the spinal cord injured but little has been done to explore the impact of such an event on the marital interaction or on specific dyadic roles. Moreover it is necessary to understand the various changes the dyad goes through to accommodate a spinal cord injury. Until such studies are undertaken, the SCI will continue to be only partially treated. A treatment program cannot be considered adequate until the SCI is understood with the social context from which he came and from which he shall return. It is with this view that this exploratory study was undertaken.

CHAPTER II

REVIEW OF RELATED LITERATURE

The purpose of this review is to examine the available literature concerned with the inter-relationship of the spinal cord injured and the performance of three major marital roles; breadwinner, social companion and sexual partner.

Though the focus of this research was on the SCI marital dyad, to view the role changes dictated by disability more objectively, it is first necessary to examine these roles within an able-bodied marital dyad and determine how to assess their worth to each partner. With a spinal cord injury, both partners must make changes in their behavioural repertoire but the most dramatic changes occur in the husband as a result of his permanent physical disability. To understand the marital dynamics post-injury it is essential to investigate some of the specific effects of a SCI on the husband as it has implications for his ability to perform as a breadwinner, social companion and sexual partner.

Since this study focuses upon the role functions of the SCI within the marital dyad after a traumatic event, post marriage, it would seem appropriate that there be some discussion of marital roles of able-bodied individuals. This is an important issue as the SCI will use the behaviours learned as able-bodied individuals as a reference point when

considering role adaptations. Two major areas will be presented: the able-bodied and the spinal cord injured.

ABLE-BODIED

The organization of social life, of social roles, and of the social division of labour in its widest sense is predicated on the assumption of normal biological functioning (Hilbourne, 1973).

There are rules which define for us, in a given situation, the manner in which we will behave and how others should respond to us. A disability requires a new behavioural repertoire which now may not be appropriate for a previously defined situation - marital life. The spouse is also required to modify her behaviour, taking on new roles and being forced to give up others. Extra burdens, tasks and responsibilities, are taken on usually in addition to those roles that she would normally be expected to assume. Roles such as homemaker and child care provider still continue but, there can be a loss of flexibility in role playing (Hilbourne, 1973).

Marital Roles

Though each marital relationship is unique there are some role interactions that take place with a certain degree of regularity (Goode, 1964; Christopherson, 1968). Nye & Berardo (1973) identified seven marital roles in their paradigm: provider, housekeeper, sexual partner, recreational, kinship, therapeutic (emotional support and

personal-helping behaviour) and child care-socialization if children are present (Chadwick, Albrecht & Kunz, 1976). The same seven roles were used by McNamara and Bahr (1980) for their study on the dimensionality of marital role satisfaction. Their one adaptation was to separate the child focused area into two variables, preschool child care role and socialization role. Schafer and Braito (1979) identified a shortened five item role list but one similar to the above named roles. The five roles identified were: salary or wage earner, homemaker, companion to spouse and sex partner. It appears that these last five role functions could be considered as central to the marital relationship.

Frank, Anderson and Rubenstein (1980) for their study on marital roles identified from the literature eight role areas. These areas are complementary to the five core roles previously discussed but are operationalized:

1. caring for home, cooking and shopping (homemaker);
2. making major family decisions (power);
3. having a career (breadwinner or contributor);
4. being sexually faithful;
5. having responsibility for care of children;
6. being sexually aggressive;
7. having interests and activities which do not include spouse (negates companion role);
8. determining how money is spent (power and related to breadwinner).

It would seem appropriate then to expect that the marital dyad under study would have engaged in varying degrees, in the five core marital

roles of breadwinner or provider, parent, homemaker, sexual partner and companion prior to the husband's disability. Of these five roles, that of breadwinner, social companion and sexual partner were explored in this study. For the husband, the role of homemaker and parent though important, have a greater importance for the family (man, woman and children) and the roles of breadwinner, social companion and sexual partner would appear more critical to the couple. The latter three would be directly affected by the disability. Discussion on role change, as it is influenced by a traumatic event is included under The Spinal Cord Injured.

THE SPINAL CORD INJURED

Disability can be viewed in several ways. Medically it is a condition of impairment, physical or mental, having an objective aspect that can usually be described by a physician (Hamilton, 1950). Sociologically, it has been defined by Haber and Smith (1971) as "the inability to perform usual role activities as a result of a physical or mental impairment (loss of function) of long-term duration" (p. 87). In view of the present study some of these roles would include spouse, sexual partner, breadwinner, worker, etc. In any situation, the orientation of the observer will affect his appraisal of disability. In the case of a spinal cord injury the usual observable phenomena is the paralysis of the lower extremities and lower part of the trunk in paraplegia and in quadraplegia the paralysis of both upper and lower

extremities as well as the trunk. There are also predictable impairments of sensory function corresponding to the level of the cord involved by disease or actual trauma (Comarr, 1971).

With both paraplegia and quadriplegia there is impairment of one type or another in genitourinary and sexual function. The key to the symptoms of a spinal cord injury is the level of the actual cord involvement; this will also determine the area of sensory and motor loss. The type of injury, a complete or incomplete lesion will also determine the degree of impairment and residual function. For the purpose of this study, spinal cord injured (SCI) will refer to both paraplegia and quadriplegia and where the differences are significant they will be noted.

With the quadriplegic, normal activities of living which require neuromuscular function are grossly impaired (and many physiosocial abilities are temporarily lost) because of impairment of hand function, loss of joint range, muscle strength and co-ordination. Activities such as feeding, dressing, bathing, ambulation, and in addition, the physical preparation for sexual activity must be delegated to others, particularly in the early stages of disability. There is a need for a great deal of personal and social adjustment in response to the effect of sudden, often unexpected disability.

The paraplegic, with the use of his upper extremities and hands does not require the same amount of physical assistance; though he too has to face the major problems of psychosocial re-adjustment. Depending on his seating and standing arrangements he may be perceived as able-bodied. Some individuals with low lumbar/sacral lesions may also be able to walk. This is usually accomplished with the aide of long leg braces or

other orthotic devices. Difficulties arise when the expectations of others based on an "able-bodied perception" are not met by the individual because of residual handicaps unseen by the casual observer. Some paraplegics would rather deal with this situation than identify themselves with a disabled group. To be labelled handicapped is to be labelled deviant (Wittkower, Gingras, Mercier, Wigdor & Lepine, 1954; Hilbourne, 1973; Hohmann, 1975). The stigma of being handicapped is not restricted only to the patient. It often places restraints and constraints on those who enter into social relationships with him.

It is well documented that illness and in this case disability, necessitate changes in some segments of the behavioural repertoire of those involved (Christopherson, 1968; Stone & Shapiro, 1968; Ludwig & Collette, 1969; Thomas, 1970; and Carpenter, 1974). The consequences of these changes has been described by authors under a variety of titles: role conflict (Thomas, 1970); role strain (Fink et al., 1968; Gibson & Ludwig, 1968; Kutner, 1971; Wittkower et al., 1954., Bursten, 1965); role stress (Fink et al., 1968; Stone & Shapiro, 1968); sick role (Parsons, 1951; Gordon, 1966; Christopherson, 1968; Skipper & Hallenbeck, 1968; and Thurlow, 1970; Segall, 1976); and role reversal (Christopherson, 1968; Dinsdale, Lesser and Judd, 1971; Hohmann, 1975b; Trieschmann, 1978; Crewe et al., 1979).

Given the wide range of role dynamics observed, three roles, breadwinner, social companion and sexual partner were believed to be of importance for this study.

As Breadwinner

There are not any studies that specifically investigate the effect of a spinal cord injury on the breadwinner role. As the role of breadwinner means the ability to generate sufficient income to put 'bread on the table', it would seem appropriate to review the employment potential of individuals with spinal cord injuries and the financial implication of the disability.

Employment potential. As previously noted paraplegia and quadriplegia result in severe alterations in the motor and sensory behaviour of the individual. The paralysis of all four limbs in quadriplegia and the lower extremities in paraplegia usually preclude the individual from returning to their previous type of employment. If a return is at all possible, it requires restructuring of the job situation, either in task demands or actual alteration to the physical environment. Buildings, washrooms and cafeterias must be wheelchair accessible as this is the usual mode of transportation with a loss of independent ambulation. Though a paraplegic still has his normal hand function (unless a secondary injury has produced changes) his lack of independent mobility would severely restrict returning to any job outside an office orientation.

The employment literature on the SCI all contains some bias. Trieschmann (1978) reports that the data are heavily influenced by self selection of subjects in questionnaire studies, by agency controls and by often including subjects other than the traumatic SCI. In addition, the amount of time spent in gainful employment, the level of lesion, and the type of functional loss and the age of the subjects are often not

reported. This makes it difficult to compare studies. It was, however, Trieschmann's (1978) opinion that approximately 13% - 48% of SCI persons become involved in some form of competitive employment.

There has been a number of variables identified as predictors of successful employment: higher level of education, age, stable pre-disability employment, ability to drive a car (Goldberg & Freed, 1973; El Ghatit & Hanson, 1975; Levenson & Green, 1965).

In two extensive studies, Goldberg & Freed (1973, 1976) followed 21 persons for four years post disability. They found 14% employed and 34% in school or homemaking. Individuals who had formulated concrete vocational or educational objectives had less difficulties in finding work. Those with less disabling sequelae were more optimistic and more motivated to return to work which was in keeping with their abilities and interest. Older individuals were more optimistic and objective on their self assessment, while younger people seemed more overwhelmed by their disability and concentrated more on their survival.

The severity of the disability or marital status per se was not associated with productivity but pre-injury level of education was associated with post disability employment.

Deyoe (1972b) studied 219 service and non-service spinal cord injured veterans and found 62 of them gainfully employed at the time of the interview. Though the material presented does not permit income source analysis in any way it was reported by the author that only seven non-service veterans had positions with sufficient income to preclude any form of pension or benefit. Though there were 99 non-service veterans in the sample, there are no data to indicate how many were included in the

employed category. The point here is succinctly stated by Deyoe.

Therefore, it may be concluded that a veteran with service connected disability often can afford not to work, while a veteran with non-service connected disability as often cannot afford not to work (p. 528).

For a Canadian population, there are some fundamental differences. As Canada does not have mandatory military service few individuals with a SCI would have military pensions ensuring reasonable incomes and benefits. Though there is national health care system this would only affect the medical coverage which would be similar to that supplied by Veterans Affairs in the U.S. Unless an individual was covered by a company plan or an individual disability insurance policy there would be no guaranteed income for him and his family. This would leave welfare or, if appropriate, some legal settlement as the only alternatives to income gained from employment. The other major option is to have the spouse become the major income earner and reverse the breadwinner role (Carpenter, 1974; Christopherson, 1968).

There is another area that affects employment which is directly related to the disability - personal independence. This includes control over bowel and bladder and transportation. Independence in transportation is noted for gainful employment out of the house (Trieschmann, 1978) but in some cases this is not enough. The actual place of employment may not be wheelchair accessible.

Lack of bowel and bladder control was cited as the first and second items of importance on a 20 point social discomfort scale (Dunn, 1977). Without adequate social control of these bodily functions, it is highly

unlikely that an individual would risk spending large blocks of time away from home. More specific discussion of the implication of loss of bowel and bladder control will be presented under sexuality and the spinal cord injured.

Though a spinal cord injury is a severely disabling event, according to the data available it does not preclude the individual from obtaining gainful employment. The difficulty is in interpreting the above statement as the studies available do not allow us to make reliable predictions on a specific individual's potential to remain employed.

Financial implications. Even though employment is eventually possible for some SCI individuals, a long term disability can impose severe economic hardships on the family. Reorganization of money management is often essential. With this, there is usually a need to shift the responsibility for this task from the disabled husband to the wife. As a result there may be a power change in the dyad, as money provides access to resources.

The costs that the dyad could be faced with are direct costs for medical services and equipment or indirect costs because of a loss of potential income through changes or loss of employment status (Litman, 1964; Christopherson, 1968; Nagler, 1950; Dinsdale et al., 1971; Kerr & Thompson, 1972; Carpenter, 1974). The disabled are among the most economically disadvantaged members of the country and particular hardship is felt when the disabled individual is the family breadwinner (Gibson & Ludwig, 1968; Berezowsky, 1979; Marra & Novis, 1959; Wittkower, et al., 1954).

Collette (1969) found in a study of disabled breadwinners that there was an increase in marital disharmony associated with employment of the wife. Wittkower et al. (1954) in a descriptive study of 400 cases of spinal cord lesions stated that the wife was often "compelled to find a job" and that a redistribution of the respective roles of each family member was almost unavoidable. This resulted in a lowering of the patient's prestige and often a perceived loss of power. The power structure of the family shifts when wives are employed giving them a greater voice in economic decisions (Blood & Hamblin, 1958).

In a study of pre-injury and post-injury marriage of individuals with spinal cord injuries, both groups tended to be happier with living arrangements and social life and somewhat less satisfied with their sex life, financial situation and employment status (Crewe, et al., 1979).

The ability of two families to resolve the crisis of the working father who had suffered a stroke was studied using Montgomery's model of family crisis (Berezowsky, 1979). The family that could problem solve promptly and make the necessary modifications in the financial and role distribution areas was able to resolve its crisis satisfactorily. The family which lacked these skills continued to be dysfunctional particularly in interpersonal roles.

Disabled husbands of working wives are more involved in household tasks than those of non-working wives. Also there is greater disagreement (20% difference) between husband and wife on the performance of household tasks (spending money and helping around the house) in dyads with working wives than those with non-working wives. Though there was a difference between groups the relationship was not significant. In a

similar study, Ludwig and Collette (1969) found that severely disabled men (many different disabilities) were less likely to respond positively to the item "the man is always head of the household"; and fewer severely disabled men were involved in computing the family income tax and in deciding on the purchase of a new car. The difficulty in these studies is that neither of them had any data on these role functions prior to disability. There was no objective data to indicate that there was any change in the role functions because of disability. Ludwig and Collette's work in 1969 may have used a somewhat archaic definition of sex roles in marriage and neither study accounted for the age of the couples and the length of time they had been married. It is quite possible that younger couples married more recently may display more equality and less structure in role performance (Trieschmann, 1978).

The disabled husband and father is much less likely to return home if he is unable to partially fulfill the instrumental role he had prior to disability and if he is to be dependent on the wife's earnings. Satisfactory role performance rather than socio-economic factors were related to marriage stability (Deutsch & Goldston, 1960; Nagi & Clark, 1964; Christopherson, 1968; Litman, 1964; Nagler, 1950; Wittkower et al., 1954). Individuals who have undergone extreme modifications to role functions can be quite satisfied with the new arrangements, if the substitute role is perceived to be challenging and to have worth.

Summary

The role of the breadwinner is traditionally assigned to the male. When a married, employed man sustains a spinal cord injury his ability to

maintain this role is usually lost. Though there is sufficient data to indicate that returning to the work force is possible for some, it usually means accepting a change in position or a new occupation and a significant decrease in earnings. For those who cannot return to work, major role modifications must take place. The wife may seek employment to supplement disability benefits or she may become the primary income earner. This can result in a loss of status and decision-making power of the husband within the dyad. The satisfaction with new role functions appears to be dependent on the individual's perception of his contribution to the family rather than his level of disability. The limited data available seem to indicate that marriage stability, (i.e. maintenance of the relationship), is not associated with socio-economic status alone but is more associated with the satisfactory re-organization of marital sex roles. The next marital role reviewed is that of social companion.

As Social Companion

Inherent in the companion role are the various social role functions within the dyad and within the family. The literature available on the spinal cord injured and their social roles is very scant. It is therefore necessary to review the area in the broader context of sociological adjustment.

Role socialization. As previously noted the handicapped are often perceived as "different" or "peculiar" or "deviant". Davis (1961) states that being handicapped is a threat to sociability in four areas. The handicap becomes the focus of interaction to the exclusion of other

topics, it has the potential for "inundating expressive boundaries", it is discordant with other personal attributes and, finally it poses some ambiguity as a predictor of joint activity. Each new situation presents a complex interactional pattern. Taking these four areas into account, the social outcomes will depend on the handicapped individual's ability to normalize the situation and the interaction. The normalizing behaviour of significant others (S.O.) also takes on more prominence. The latter become significant actors in determining if normalization will be a success or a failure. This was also supported by Hilbourne (1973).

With married individuals, the spouse is the most likely person to be involved. The process would be more complex when other family members such as parents are in close proximity and become primary actors too. Davis (1961) presents three stages in the normalizing process:

- 1) fictional acceptance that is governed by highly elastic assumptions of normalacy and equity in social encounters; 2) facilitating normalized role-taking that requires the normal to identify with the projected images, attitudes and self concepts of the disabled, and reject his previous view of deviance; and, the third stage, the institutionalizing of the normalized relationship. Stage three involves educating the new acquaintance on what to do in social situations when confronted by physical barriers such as stairs and by social obstacles such as over-helpful strangers. Being the companion of a disabled individual has more responsibilities and requires a delicate balancing of concessions for the disability and expectations of the person.

Cogswell (1968) described the self-socialization of paraplegics in the community. The social stigma of disability is dependent on the

person's self concept, his skill in managing other's definition of him, the particular social setting and the type of social other. Social stigma can be diminished by reducing social encounters, and limiting them to situations or groups where the stigma is less salient.

Cogswell does not present any data, but rather reports observations from personal experiences and interviews as the basis for her socialization rationale which follows.

Spinal cord injured patients post discharge tend to allow pre-injury relationships to wane. New friendships are sought with people of lower social status. These individuals are often decidedly younger or older or less attractive in other ways. This seems to be a means of allowing the self to readjust and take on a projection of worth. As the skill of eliciting definitions of "worth "about themselves from others develops, they take greater social risks by seeking relationships with new individuals with equal status.

The rehabilitation process is a symbolic one, each reaccomplishment of an old skill such as dressing, feeding, sitting up becomes an indicator of progress. This progress and the ultimate level of independence gained will be one of the prime indicators of personal change necessary for resocialization.

As previously cited, Dunn (1977) investigated social discomfort in the SCI. The findings indicated that the situations which produced the greatest discomfort were those concerned with the elimination functions, public embarrassment and refusing unwanted help:

Patients who were 35 years of age or older admitted to having more difficulty than younger patients. There was a statistically

significant inverse relationship between staff ratings of overall adjustment and the amount of social discomfort experienced. Only age proved to be a statistically significant demographic variable in the amount of social situation discomfort experienced.

The implications of these findings are that concern over these areas particularly the lack of bowel and bladder control is sufficient to restrict social interaction (New, Ruscio, Priest, Petritsi and George, 1968).

In a study of conceptual style and life satisfaction following spinal cord injury, Carlson (1979) found four distinct clusters of life satisfaction measures: 1) family relationships; 2) intimacy, subjective reactions and personal maintenance; 3) social presentation of self; and 4) tension and its management. The highest correlation was between clusters two and four ($r = 0.43$) indicating that individuals who are able to manage tension well are more likely to relate well on an intimate basis than those who have high degrees of tension and poor resolution techniques. The importance of these findings is that significant others should be assisted along with the client in order to work through changes in the relationship.

Kahn (1969) reviewed the social rehabilitation of the SCI using a medical management framework. During hospitalization, clients are divested of clothes and personal belongings. They are also depersonalized and forced to play regressed roles. The already traumatized self image is further damaged by the loss of privacy and of control of personal affairs. During this time social deformities and sores can be formed. Prevention must take the form of social

range-of-motion exercises to prevent withdrawal and family disintegration. Social pressure areas such as premarital functions between client and family members, and pressure which are a result of disability dictated role changes.

Family members must frequently play quasi-professional roles in meeting the client's needs. The development of social distance mechanisms on the part of the S.O. are required to reduce the strain of excessive emotional involvement. Often it deprives the client of the much needed support of a close and sometimes intimate relationship.

The return to social functioning requires realistic goal setting and preparation of resources to assist the family. Various types of assistance may be required such as financial, home help, and medical to prevent physical status deterioration. Prevention of the disuse of the client's and the families own resources are also essential (Kahn, 1969).

Personal characteristics. Breaking through the various barriers to return to active participation in social and community activities requires an intelligent, resourceful, outgoing person (Mueller, 1962). Litman (1964) found that patients who led an active role in society prior to injury were less likely to succumb to the dependency and possible social isolation. A history of extensive physical activity seemed to provide incentive to attain independence.

In many instances the social world of the disabled dwindles quickly. Old friends stop coming to call, the family who have become the client's social matrix find other ways to spend leisure time. The wife may be too tired emotionally and physically to provide much in the way of companionship (Christopherson, 1968). Crewe et al. (1979) found that

both pre-injury and post-injury groups led active social lives, getting out at least once a week. In both groups, the family saw the disabled person as a significant contributing member, not as a burden. This was similar to Deyoe's finding of active social and recreational interactions of paraplegics and their families (1972a). Other studies have found that the major activities of the SCI are passive, cognitive and solitary, such as reading, watching T.V., etc. (Runge, 1966; Rogers & Figone, 1979; Ludwig & Arndt, 1980).

Seymour (1955) found that quadriplegics consistently scored higher than paraplegics on a social adjustment scale. The differences were significant at the .01 level. Social adjustment was described as a "surface phenomenon" in this study to explain the results. Paraplegics were seen by staff to be less compliant, irritable and demanding which were manifestations of their internal stress and struggle to organize self and personality. The better social adjustment scores of quadriplegics were attributed to the staff's perception of the clients on a management basis. The greater functional loss of the quadriplegic will automatically reduce movement and choices of action. The clients' lack of overt attempts to return to previous activities was seen as conformance. As stated by Trieschmann (1978) this work was done in the early 1950's and does not present any validity data. Many salient factors such as length of disability, and place of residence are not noted so the results must be treated cautiously.

Fink, Skipper and Hallenbeck (1968) examined marital relations when the wife had contracted a disabling disease. Though the types of disabilities within the sample were not reported there is reference to

polio within the text. Their findings indicated that there was no relationship between the wife's disability status and the husband's need satisfaction as based on Maslow's hierarchy or the degree of disability and total marriage satisfaction. Upon separate examination of the seven aspects of marital satisfaction: companionship, social status, power, understanding, affection, marital esteem and sex, it was discovered that companionship satisfaction did correlate significantly with the wife's physical mobility. This can be explained by the husband having to spend more time at home with his severely, disabled wife, therefore reducing the time available to visit his own companions outside the home (Fink, et al., 1968; Hilbourne, 1973).

Summary

Society at large is ambivalent about the disabled either ostracizing them or over-compensating by pampering them. There is a lack of awareness of the disabled person as an individual. The primary focus of any attention was upon the disability. The ignorance of the public about the abilities of the disabled often creates social situations which are quite stressful. To cope with this, many SCI change their reference groups or withdraw relying on their families for their social and recreational needs.

In some marriages, where the premarital personality and social resources were well developed, the post-injury social adjustment was satisfactory. For others, their social networks were markedly reduced with the major responsibility for companionship falling to immediate family members or to the wife.

There are many factors to consider when examining the companionship role in the SCI marital dyad. The husband, because of his disability may have changed his peer group, while the wife who is able bodied still has old friends as her reference group. There may be problems in selecting a reference group for social affairs. If the husband has withdrawn and also cut off old social ties the wife may not be able to have a parallel social network outside the home. Changes could occur in the choice of leisure activities. Activities could become more passive and solitary. Individuals could attempt to modify old interests or they could find new interests as a compromise for both husband and wife.

As Sexual Partner

Although there was some attention directed toward the discussion of sexuality and the handicapped in earlier years, the vast majority of the literature now available is a product of the late sixties and the seventies. Many authors are presently calling for an increased awareness and a facilitation of the sexual functioning of the handicapped. It is as if professionals in the health care field have just realized that individuals with disabilities are sexual beings. In response to this new awareness, the literature in the area has proliferated accordingly. Bibliographies have been produced to assist the professional to gather information; workshops have been presented to provide an atmosphere to explore feelings, attitudes, and communication techniques. Surveys have been done. All in all there has been a flurry of activity, all directed toward assisting the handicapped and the SCI in particular to maximize their sexual adjustment.

It would be fallacious to think that an individual who has had a normal pattern of growth, psychosocial and sexual development up to his adult years, upon sustaining a spinal cord injury, would become a totally asexual being (Talbot, 1972; Cole, 1975; Hohmann, 1975; Berkman, Weissman and Frielich, 1978).

Sexuality is a complex phenomenon composed of psychological elements of personality and drives as well as the anatomical and physiological elements that allow us to actually perform a sex act. Trieschmann (1978) said it a little differently.

Sexuality is the expression of a sex drive through sex acts within the context of the sexual identity of the person: the maleness and femaleness of the individual which is so heavily influenced by learning and one's environment (p. 112).

In analyzing both statements, the two major contributing areas to sexuality can be identified. The first is the anatomical/physiological area that is responsible for the motor and sensory stimuli. The second is the psychosocial area that is responsible for sexual identity, the regulation of drives and the learning that influences our sexual expressions which also influence the sex act. A review follows under anatomical and physiological concerns, bowel and bladder dysfunction and sex act in marriage.

Anatomical and physiological concerns. In a thorough review of information on the physical and psychological sexual functions of spinal cord-injured patients, Griffith, Tomko and Timms (1973) noted the lack of attention to sexual neuro-physiology. Nine studies of sexual function in spinal cord injured males were reviewed with a combined population of

over 2000. In a similar article Fitzpatrick (1974), summarizing the neuro-anatomy and neuro-physiology of sexual functioning stated that an erection is regulated reflexively by the sacral segments and the parasympathetic nerves, and psychologically by the cortex, subcortex, reticular system and the thoracolumbar cord segments. An erection can be stimulated through somatic efferents or central synapsis and it is therefore not vulnerable to trauma in a single segment.

Ejaculation is a more complex mechanism which requires intact function in both thoracolumbar and sacral reflex centers, as well as parasympathetic and sympathetic innervation. Therefore, it can be readily appreciated that ejaculation is a much more vulnerable function and as such, is more likely to be eliminated in the traumatized patient than erection. This is a major concern for paraplegics with a low lesion. Fitzpatrick's (1974) data primarily came from four of the nine studies used by Griffith et al. (1973).

Other sources review the implication of sexual function and dysfunction and explore the alternatives such as oral-genital sexual activity and manual stimulation open to the neuromuscular male for sexual gratification (Kirby, 1974; Berkman, 1975; Cole, 1975; Mooney, Cole & Chilgren, 1975; Paradowski, 1977; Berkman et al., 1978). Comarr (1971) who has written many articles in the area, reviews the neuro-physiology of sexual function, frequency of coitus, progeny and under "related observations" states that some patients report oral-genital sexual activity. It is difficult to accurately interpret his findings as the results are stated in percentages with few references to total numbers under consideration. The patients referred to under various topic areas

come from different studies he has conducted within the last eighteen years.

In summary the area of sexuality and the SCI has had the greatest number of articles dealing with anatomical and physiological concerns such as erections, ejaculations and the ability to have orgasms. Genitourinary function and sensation is lost in complete lesions and erections occur by reflex. With incomplete lesions the probability of psychogenic erections increase and there is usually no impairment of erective capacity. With high cord lesions, the reflex arc is intact: A flacid penis is the usual outcome of a complete lumbar lesion and reflexive activity is non-existent. In complete sacral lesions, flacidity is constant. The findings indicated that coitus is possible following a SCI, but each case must be reviewed independently.

Bowel & bladder dysfunction. Bowel and bladder function have a common nerve supply with sexual function; therefore just as the SCI will have some sexual dysfunction, there will also be an alteration to bowel and bladder function.

This can be devastating in a sexual relationship. There is a primary and secondary concern for alterations in bowel and bladder function as they relate to sexual activity. The primary concern is the specific impairment of a previously automatic and independent function - biologically and psychologically. Biologically there are numerous medical conditions that can develop as a result of impairment of excretory functions. Psychologically the impact of bowel and bladder dysfunction on the individual has been described in terms similar to the impact of sexual dysfunction. Previous internal conflicts are now

externalized and symbolically represented by alterations to bowel and bladder functions. A previously private, automatic and independent function becomes more of a public act requiring the help of another individual (Grynbaum, Kaplan, Lloyd & Rusk, 1963; Symington & Mackay, 1966; Comarr, 1971; Fitting, Salisbury, Davies & Mayclin, 1978). Firstly the assistance of medical personnel is required and later if independence is not obtained, spouses, S.O. or hired attendants must help. A response to this change in status is often anxiety and depression which can then result in alterations to the self concept (Thom & Von Salzen, 1946; Mueller, 1950; Knorr & Bull, 1970; Weber & Wessman, 1971; Fitzpatrick, 1974; Fitting et al., 1978; Stewart and Rossier, 1978). At this time there are a number of defence mechanisms and adaptive responses commonly used to protect the self. In regards to the SCI some that have been identified, are sublimation, compensation, withdrawal, avoidance (Thom et al 1950; Nagler, 1950; Seymour, 1955; Mueller, 1962), others are denial intellectualization, aggression and dependency (Mueller, 1950; Seymour, 1955; Siller, 1969; Hohmann, 1975b).

The secondary concern is a result of the embarrassment over bowel and bladder "accidents" that can happen at any time. Without the knowledge of control individuals will not risk social and intimate interactions and in particular may avoid sexual encounters (Nagler, 1950; Rusk, 1971; Cole, 1975; Fitting et al., 1978). Hanson and Franklin (1976) found loss of bowel and bladder function to be the second greatest concern to paraplegics and quadriplegics on a four item list. Yet other authors have reported that bowel and bladder function is not a concern (Grynbaum et al., 1963; Symington & Mackay, 1966; Fitting et al., 1978). This may

be explained by the wide variety of lesion types studied and a particular sample bias as well as the variations in rehabilitation programs that individuals may have had.

In regards to being a sexual partner, control over bowel and bladder function is important for the sex act and the psychological well being of the individual. The fear of an "accident" can be a major deterrent in becoming sexually intimate.

Sex act and marriage. Thus following a SCI certain kinds of sex acts may have to be abandoned or modified. Someone wishing to remain sexually active must then explore alternatives (Comarr, 1971; Mooney, Cole & Chilgren, 1975; Kirby, 1974). The genital area is the primary but not the exclusive erogenous zone; many areas of the body may participate in producing a sensory sexual response. There are many types of sex acts which can produce pleasurable sensory responses of which penile-vaginal intercourse is but one. Attitudes and social learning will determine which of these options a person considers permissible.

The following section will explore studies available on marital sex and the SCI and which have specific reference to the spouse.

Fitzpatrick (1974) studied spinal cord injured males and their wives. When asked to rate their pre-injury and post-injury satisfaction with sex, the wives of the five married spinal cord injured individuals all rated their pre-injury experiences as satisfactory (Fitzpatrick, 1974). Three reported that they were not satisfied now and in fact did not engage in any sexual activities. Interestingly all three women were married either 11 or 12 years. The two other respondents, one married five years and the other married 16 months both reported their present

situation to be satisfactory and engaged in sex once or twice a month. Of the total 14 patients interviewed which included the married group, 63% reported that they had not attempted intercourse. It would appear that some form of sexual activity should be encouraged as the attempt itself may be very significant to the spouse.

Knorr and Bull (1970) in their study, reported that during the period of the patient's depression and confusion over his future sexual states, there is an attempt to push the wife away. This can be an overwhelming time for the spouse dealing first with the tragedy and then with the increased demands of the husbands. The results can be a withdrawing of the wife with deleterious effects on the patient.

Wittkower et al. (1954), in one of the few Canadian studies, reported that most women were able to cope with the strain of their husband's SCI. There were six examples of severe distress, one suicide, one abortion and divorce, one divorce, two separations and one case of a precipitated personality disorder. Unfortunately there is no indication of how many of the 50 people interviewed were married. Those women who were coping reported that, "they reassured [their husbands] as much as they could about sexual dysfunction and cared for the children to the best of their ability" (p. 113).

The early work of Comarr (1962) concluded that marriage stability was not dependent on the ability to engage in intercourse as many pre-injury marriages remained intact despite the husband's sexual dysfunction.

El Ghatit and Hanson (1975, 1976) studied the outcome of pre-injury marriages of SCI males (N=333). Though they did not study the influence of sexual dysfunction on marriage outcome, two areas of study, the

presence of children, and the response to the question of the effect of disability on the marriage termination allows some extrapolation. The birth of children post-injury which means that coitus took place was associated with higher divorce and separation rates. This relationship also held true for marriage which had children born before the injury. It would appear that the presence of children creates additional stress which can influence marriage stability.

Sadoughi et al. (1971) who studied sexual adjustment in the chronically ill and found for men that, "the correlation between marriage change scores (satisfaction) and frequency change scores indicate that decreases in the rating of marriage related to the decrease in sexual frequency" (p. 316). The heterogeneous disability group studied did not include the spinal cord injured. Though the sample had chronic disorder, emphysema, arthritis or permanent changes such as an amputation none would have had a primary sexual disorder as does the spinal cord injured. It would seem then that their responses given without the presence of a primary sexual disorder could then be used to predict the responses of the SCI.

Though the paraplegic group studied by David, Gur and Rozin (1977) was married post-injury 14 of the 16 spouses did not know what to expect of their future husband's sexual functioning. This would make their situation similar to the wives of patients injured post marriage. In most cases pre marriage expectations in regards to love, home, mutual understanding and acceptance, social and economical concerns were not met; especially in the area of sexual enjoyment and having children. One wife of 12 years was quoted as saying, "Can you imagine all the possible

secretions, smells, and other things one has to suffer in order to get a very small amount of sexual gratification" (p. 199). Only two of the 16 couples were in the process of attaining a divorce but seven of the remaining 14 had considered it at one time but decided "to suffer and survive together" (p. 200).

Guttman (1964) reported that the dissolution of the marriage in some instances was because of sexual frustration on the part of the wife or her extramarital relations. After reviewing the literature on the sexual functions of the SCI, Griffith et al. (1973) stated that "sexuality" in marriage takes many forms and must be considered in a broader context than intercourse. Some marriages specifically reported "no continuing sexual intercourse" and others reported the most casual of sexual activities such as petting and kissing. Obviously there are many forms of intimate interpersonal relationships but fundamental to all is an effective communication process between partners.

Crewe, Athelstan and Krumberger (1979) compared pre-injury and post-injury marital relationships. In this study the spouse was also interviewed which is an important addition to other studies of marriage and the SCI. Areas studied were medical and employment status, social life, physical dependency, sexual functioning and satisfaction with various aspects of life. Respondents in both groups (N=55) were less satisfied with sex life, finances and employment than social life and living arrangements. There was no significant differences between groups. On self reported satisfaction, one third of the pre-injury group (N=24) claimed satisfaction with no sexual activity at all as compared to only one of the 31 people in the post-injury group.

Two measures of adjustment were taken throughout the study, the self-report of client and the judged adjustment rating of the interviewing psychologist. In the area of sexual adjustment the psychologist's rating of sexual adjustment favoured post-injury marriages (the χ^2 score just fell short of significance at the $p < 0.05$ level). Of the six areas rated, the raw scores for satisfaction of sex life for pre-injury clients had the lowest rating (2.94) on a five point scale. For post-injury marriages sex life satisfaction was the fourth highest at 2.31 and financial satisfaction was the lowest with a 2.60 rating. All ratings reported in this particular article were those of the clients, it is expected that the analyses of the spousal responses will be published at a later date.

Summary

The sexual adjustment of the spinal cord injured is a complex area that plays a very significant role in marital adjustment. For the spinal cord injured no simple explanation can be offered on the dynamics of sexual adjustment post-injury or its direct affect on the marital dyad. From the few studies available there is some indication that sexual dysfunction and a lack of specific knowledge of what to expect of the injured partner is a common experience for these people. Individuals used to engaging in sexual acts without verbalization are suddenly faced with having to employ verbal interaction to explore and to fulfill sexual desires.

Not only did new techniques have to be found, couples had to learn about appliances used for bladder control, contend with automatic bowel

and bladder excretion as well as physical changes in body structure. Muscle spasm, atrophy and flaccidity all affect mobility and independence. Loss of personal autonomy, power over self and changes in body image and self concept affect sexual performance as well as the total personality structure. Depression and the abnormal use of some defence mechanisms made it difficult for rehabilitation and adjustment to the disability to take place. The wife was often called upon to assume new role functions such as nurse and orderly, to modify other role functions such as sexual partner and to maintain many other functions such as wife and mother. The net result in many cases was decreased sexual activity for some and complete abstinence for others.

Marital Adjustment

As can be seen from the previous literature there are many changes that can occur in the role functions of the spinal cord injured as breadwinner, social companion and sexual partner. Some changes are a direct outcome of the alteration in the individual physical status and loss of function. Other changes are influenced by the individuals' experiences in their able-bodied life and by the experience they gain following their spinal cord injury. The adaption made by the SCI and his ability to perform as breadwinner, social companion and sexual partner is dependent on the interaction and integration of all that has gone before and all that can be relearned.

Coupled with this dynamic change, is the spouse's response to her husband as breadwinner, social companion and sexual partner. There can be little doubt that a traumatic injury such as a spinal cord injury will

have a great effect on the post-injury equilibrium of the marital dyad. It is important to investigate the changes that take place in role functions and the ultimate outcome of any role reorganization or change that has occurred. The research questions follow:

RESEARCH QUESTIONS

In all three major role functions there are conflicting reports on the ability of the SCI to satisfactorily fulfill the roles' particular demands.

The level of injury, its severity, the pre marital personality and its stability, the pre-injury work, sex and social experiences of the individual all play a significant and interrelated part in the individual's response to a traumatic spinal cord injury. No matter what the level of personal adjustment of the individual is, there will be a need for role modification and change within the marital dyad. Some of these changes will not be mutually satisfactory to both partners.

The objective of this study was to review the marital adjustment of spinal cord injured men, married before injury. Having now reviewed the literature the general research objectives can now be stated more specifically and are presented as follows:

1. How has the dyad adapted to the changes dictated by the husband sustaining a spinal cord injury?

2. What are the present role behaviours of the dyad for:
 - a) the breadwinner role?
 - b) the social companion role?
 - c) the sexual partner role?
3. What is the overall dyadic adjustment once role behaviours have stabilized?

The research findings will be presented using the symbolic interactionist's view of marriage, the marital roles and role change. The following chapter describes the nature of marital role changes following the husband's spinal cord injury using the symbolic interaction framework.

CHAPTER III

SYMBOLIC INTERACTION: A CONCEPTUAL FRAMEWORK

A conceptual frame of reference provides a systematic and consistent approach to studying and analyzing family behaviour. A framework that has been consistently identified with dyadic study, in particular the marital couple, is symbolic interactionism. It provides a unique perspective for both the dyad and the individual. Given the focus of the current study the SCI marital dyad and the investigations of the role changes that occur following a permanent disabling event, it would seem the most appropriate framework to employ. An overview of the framework identifying its basic assumptions and those concepts of significance to the discussion of the study, the self, status, role, role-taking, role-making, significant other, communication, definition of the situation and reference group follows. The application of the framework to the study of the spinal cord injured male and his spouse is also presented.

Principles of Symbolic Interaction

Symbolic interactionism takes the view that central to the socio-cultural perspective, man is a social animal. His very biological nature precludes him from living outside of social groups except in the most extenuating of circumstances. Man is dependent upon his social

environment as well as upon his biology to sustain his existence.

Through his self development and interaction man has imposed on his environment an elaborate superstructure of a symbolic nature. This has resulted from his capacity to create and use utterances and gestures with an agreed upon meaning. In order to interpret his environment and to react to it through symbols, he is both an actor and a reactor.

His mental capacities allow him to store and transmit these symbols over a long period of time. This ability and the preservation of symbols is responsible for the eventual outcome of a super organic structure-culture. Culture provides a complete design for living (Edwards, 1972). But within this design for living, the social act or interaction is the focus allowing for a dynamic analysis of a persistent and stable pattern of behaviour. Language is the link between mediation, interpretation, interaction and social process.

Key Concepts

The self is central to personality development and is a repository of social influence on the individual as well as the source of its interactional energy and initiative. As stated earlier, it is responsive to socially recognized categories and roles and reflective in nature. The self is not a theory or object to be identified but a facilitation between "I" and "me". Self-concept, self-image, self-esteem are all products of the self-reflection. The self is further developed through the defining of one's behaviour in terms of the expectations of others in a social process (Schvaneveldt, 1966; Stryker, 1972; Gecas & Libby, 1976). Also involved in the defining of self, is the salient process of

role-taking, which involves anticipation of responses of others and the modification of one's own behaviour in light of those anticipations in a particular social act. The process may occur with or without emotional involvement and usually with a particular other such as a reference group or a significant other. These "others" serve as the locus for perspective for the individual to view himself and heightens the intimate relationship between self and audience.

The significance of "others" is determined by their status or position in a socially recognized category. The organizational structure serves to order behaviour within the category and sets expectations for the performance of these behaviours which then defines a role (Stryker, 1972).

The creative or adaptive response to role taking, a cognitive process is role-making, a behavioural process. Novel responses may arise through the reaction of the individual to insights gained through role-taking. In the process of assessment, objects and interactions must be ordered, requiring the various symbols and cues in the interaction and the environment to be categorized. Each new situation must be represented to the individual in symbolic terms in order to facilitate a response; the individual must define the situation.

Fundamental to the interactional process is communication by verbal and non-verbal forms. It is through the analysis of the communication process and role performance that symbolic interactionism makes its most valuable contribution to sociological research (Stryker, 1964; Schvaneveldt, 1966).

DEFINITIONS

Communications

The exchange of meaningful symbols through verbal and non-verbal behaviour is communication. It refers to the ability to interchange specific symbols meaningfully.

Definition of the Situation

This is the symbolic decoding of the stimuli in a social situation in order to determine one's response. It sets the stage for action.

Reference Group

This is a significant group to the individual that is used as a criterion for behaviour and thought. It has the ability to influence and sanction.

Role

A pattern of consistent actions which are influenced by the expectations of others in a social setting and distinguishable from other response patterns is called a role.

Role-Taking

The internal process of anticipating the response of another and as a result, the modification of one's own behaviour.

Role-Making

This refers to the alterations and adaptations to existing roles. It often results in a novel or original response as a result of role-taking.

Status

This refers to the positive recognition one receives from others which allows a position in a group to be maintained.

Significant Others

Individuals who are ranked high on the status-continuum and given priority over others are regarded in this way.

Self-Concept

The self is one's own evaluation of worth as it is derived through a social process. A positive self concept provides the impetus to initiate and to engage in new situations and new social interactions.

Application of Symbolic Interactionism to the Study of the Spinal Cord Injured Marital Dyad

As has been already presented in the review of the literature, a spinal cord injury and the resulting permanent disability sustained by the husband will produce a major disruption in role functions within the family and its marital dyad. The sociological framework most often used to study marital dyads and the SCI is symbolic interaction (Hohmann, 1972; Litman, 1964; Cogswell, 1967, 1968; Hilbourne, 1973; Berkman, 1975;

Singh & Magner, 1975; Berkman et al., 1978). Specific concepts of the framework will now be applied to the situation under study.

The self-concept of the individual is very fragile following a spinal cord injury, resulting in the use of many defence mechanisms such as identification, withdrawal, avoidance, and denial (Thom et al., 1946; Nagler, 1950; Seymour, 1955; Mueller, 1962) and other defensive reactions such as aggression and depression (Mueller, 1950; Seymour, 1955; Siller, 1969; Hohmann, 1975b). These are used to reduce the individual's stress. As this stress management is in progress, it produces fluctuations in self-concept. This will influence the individual's will, desire, cooperation, and interaction at that time, as well as alter behaviour (Litman, 1964; Cole, 1975; Singh & Magner, 1975).

The defining of one's behaviour in terms of expectations of others requires the interpretation of symbols in the environment, verbal and non-verbal. This refers to identifying the norms of a social group. For the disabled, role functions are altered firstly by new norms which is a function of patient's prognosis held by rehabilitation personnel and secondly by the patients significant others which is a function of their view of the sick role (Gordon, 1966). As the patient, through the rehabilitation experience, learns more about his abilities and limitations, there is an abandoning of the previous role of able-bodied, an identifying with the new role of disabled, an overemphasizing of the new role for role skill mastery and finally an integrating of the new role into the individuals' role gestalt (Cogswell, 1967). Cogswell (1967) calls this the socialization process experienced by the SCI, in particular paraplegics becoming incumbents of the disabled role. It is

the last two stages, role mastery and integration that will be examined here focussing on the role of breadwinner, social companion and sexual partner.

The disruption of role functions is not only experienced by the SCI but also by family members. The rules which lend predictability and certainty to social interactions are no longer appropriate. The definition of the situation must now change with the introduction of a disabled actor. Often the expectations of the family are far below the potential of the individual which makes resumption of old roles difficult.

Role-taking then becomes an important process. If we assume that because of disability, there are disturbances in role-taking accuracy of the key actors, SCI and spouse, then in a given situation, which may be a sexual act, there must be some changes in the S.O.'s. behaviour.

Role-making or role modification is imperative. The S.O. (wife) through the internal decisions based on her analysis of the actor (SCI) in the sexual act must adapt her intended behaviour to be more congruent with the actor's anticipated action. The S.O., through manipulation of the actor and the situation, creates a passive sexual role for the disabled actor by assuming the dominant aggressive role. This would be contrary to the expected role functions in the sexual act and also produce a contradiction in the social scripts held by each actor.

Gecas and Libby (1972, 1976) analyzed sexual behaviour as symbolic interaction. Discussing verbal and non-verbal communication, motives, erotic imagery and socialization according to symbolic interaction concepts they set out successfully, to give the reader both a conceptual

and empirical model to view human sexual behaviour. This is very applicable to the dyads under study.

Language is rarely neutral, expressing attitudes as well as meanings and gives insight into the sexual attitudes and values of those using it. Variation in connotations associated with sexual terms was found by gender, social class and other social and personal characteristics. This can lead to ambiguity and misinterpretation on the part of the actors.

Non-verbal communication plays a very important part in our sexual interaction, as an aid to validating the interpretation of verbal sexual communication (and as a primary form of communication). It also allows for indirect sexual expression which prevents prematurely committing oneself to a given course of action.

Some of the behaviours identified by the authors in this category are smiles, frowns, winks, body postures, physical spacing, eye contact, clothing and cosmetics. There are other non-verbal communications which are more direct and can be very sexual, that is forms of touching, fondling, stroking and rubbing, etc. While the former behaviours can be interpreted by sight the latter are received by touch and pressure receptors. This is an important consideration in the later discussion of the SCI who have impaired sensory tracts and are therefore structurally limited in their ability to appreciate this basic form of sexual communication.

The concept of social script (Simon & Gagnon, 1968) is introduced which has two major dimensions: the external/interpersonal one that is the organization of mutually shared conventions which allows two or more actors to participate in a complex mutual dependent act; and the

internal/intrapersonal one that is the motivator that produces the arousal or at least a commitment to action. Scripts are normative clusters setting the parameters on a given situation for lines of action. Many writers on sexuality and the SCI have used symbolic interaction as the framework for discussing sexuality - some directly (Singh & Magner, 1975; Berkman, Weissman & Frielich, 1978) other indirectly (Hohmann, 1972; Trieschmann, 1975; Cole, 1975; Berkman, 1975).

Sexual adjustment in marriage is a complex interactional pattern. Each actor brings to the marriage bed their premarital sexual experiences, their attitudes, knowledge and their expectations, all of which can be complementary or divergent. To work out a sexual relationship which will be mutually satisfactory to both partners involves exploration, understanding and acceptance of each others' behaviour and feelings. There must be a genuine desire expressed through verbal and non-verbal communication to improve the quality of their sexual experience on the part of both actors.

Role behaviour within a marital dyad is responsible for the integrative quality of the marriage. Changes in roles will have a direct effect on this quality and the interactional process. If the integrative quality is to be maintained there must be a degree of congruence between the actors on role, perception, expectation and performance (Mangus, 1957). Following a spinal cord injury roles do change and therefore there will be an alteration in the three previously listed variables (Thomas, 1970).

Summary

The dynamic relationship between the husband and wife has been identified as the unique unit of study for the symbolic interaction framework. It also deals extensively with the self and its development. As the self of the SCI is severely traumatized as a result of a sudden irreversible injury, this is a fundamental concept to understanding the interaction within the marital dyad after the husband's accident. The concepts of symbolic interaction are relevant to the area of study and provides a dynamic framework which can deal with change. The framework also appears to be the one most frequently used in the available sociological studies of the SCI.

CHAPTER IV

METHODOLOGY

From the review of the literature, it is obvious that there has been very little exploration of the role behaviour of the SCI marital dyad. This is a major shortcoming in family and rehabilitation research. In order to better understand the process married couples go through after the husband's injury, it is essential that marital role behaviour be reviewed and the adjustment of the dyad assessed. Without this, any anticipated counselling would be ineffective. Because this was an exploratory study, interested in noting process, a descriptive case study approach was adopted. This procedure allows for depth analysis - an excellent way to review the dynamics of change while still preserving the integrity of the unit (Wiseman & Aron, 1970).

The current study was the second stage of a two stage work undertaken in conjunction with the Division of Rehabilitation Medicine, University of Alberta Hospital (UAH) and Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta. The UAH has a large rehabilitation unit which serves the northern part of the province. Here a comprehensive program of rehabilitation drawing on the resources of many health disciplines is offered to individuals who have sustained strokes, head injuries, amputations and spinal cord injuries as well as to those who are disabled by progressive neurological disorders.

A presentation of the methodology follows which will specify the research design, the sample, the instruments used and the manner of data analysis.

Design

A case study approach was selected to explore the impact of one critical event - a spinal cord injury in the life of the marital dyad. The subsequent changes in behaviour dictated by this traumatic event, in both husband and wife, require a careful detailed analysis in order to identify the dynamics of change (Wiseman & Aron, 1970; Treece & Treece, 1977).

This approach is also useful when a study is an exploratory one. Here coupled with a depth interview it becomes possible to identify significant events, attitudes and behaviour which can affect change. In studies such as this, which seek hypotheses rather than test them, the interviewer is permitted to explore and deviate from a structured format. However, when the wording of an interview schedule is changed and probes used to gather more substantial data, the interviewer must assume more responsibility for attempting to maintain a level of interview standardization (Wiseman & Aron, 1970; MacKinnon & Michels, 1971).

Sample

As previously stated the study under discussion was the second part of a two part work, both of which were undertaken by the writer. The initial stage was a life situation survey of all traumatic spinal cord

injured individuals discharged from the rehabilitation unit within a five year period (June 1974 - June 1979). Potential subjects were identified by reviewing UAH medical records. A heterogeneous diagnostic group of 73 individuals was discharged from the unit during this time period. Of that number, 26 were diagnosed as having a spinal cord injury, but only 17 were a result of a traumatic injury and therefore eligible to receive the Life Situation Questionnaire (LSQ) (Crewe et al., 1979), part one of the study.

An initial orientation letter informed people of the joint study, explaining its purpose and soliciting their support. Subjects were informed that their participation was strictly voluntary and were requested to complete an enclosed general information sheet. It was anticipated that it would be difficult to reach some people because of address changes and it was hoped that "lost" individuals might be traced via a secondary source (Appendix A). Seventeen LSQ were mailed with self-addressed, stamped envelopes and covering letter (Appendix B).

Of the seventeen eligible subjects, six were unable to be traced, two chose not to respond, leaving nine respondents; eight males and one female. It is from this latter group (N=9) that the subjects were selected for the second stage of the study and the focus of this research - the review of the marital dyad.

The inclusion criteria were:

1. the individual had to be male and married to his present spouse prior to the time of injury;
2. the couple had to be considered to be co-habiting since the husband had been discharged from hospital;

3. the husband had to be medically classified as paraplegic, or quadriplegic
4. the length of time since injury could be no more than five years in duration.

Four individuals met these criteria but unfortunately, only two were in the Edmonton area. The third individual lived in British Columbia and the fourth resided in the North West Territories.

Instrumentation

Interview Schedule. The interview was structured by using the individual interview schedule for husband and spouse developed by Crewe, Athelstan and Krumberger (1979) for their study of pre and post disability marriages of the SCI (Appendices C & D). Its content explores the areas of concern cited in the literature such as detailed biographic and demographic information, activity of daily living functional levels, social interaction, vocational activities, support systems - interpersonal and economic dyadic interaction, sexuality and an overall self appraisal. All of these items can be regrouped to provide information on the three role functions being studied: breadwinner, social companion and sexual partner.

The interview schedule is worded to avoid ambiguity, to collect factual data and where appropriate to provide answer categories which did not force choice (Treece & Treece, 1977). As previously noted, there are disadvantages to the case study interview format, such as providing data unique only to the studied unit which cannot be generalized. The researcher can also be biased toward certain respondents and therefore

misjudge responses. It is also very costly in time and money in relationship to the amount of knowledge gained. (Campbell & Stanley, 1966; Treece & Treece, 1977).

The reliability of an interview is governed by its content, the skill of the interviewer, the interviewing situation and in the technique used for interviewing. The interaction of these variables make it impossible to test the interview's reliability statistically in this situation (Grad de Alarcon & Crocetti, 1975).

From the review of the literature, the interview schedule does have face validity. As it has been used previously by the Minnesota group in a major study (Crewe et al., 1979), it can be viewed as having content validity. It should be noted that the Minnesota group is responsible for a very sizeable contribution to the research on the spinal cord injured (Cole, 1975; Mooney et al., 1975; Held, Cole, Held, Anderson & Chilgren, 1975; Cole, Chilgren & Rosenberg, 1973; Crewe, Athelstan & Meadows, 1975).

Marital Instrument. Throughout the literature on marriage and family research there are constant references to marital satisfaction, marital happiness and marital adjustment as the dependent variable. The ambiguity and confusion over the ways in which these terms have been used led Burr (1973) to reformulate their conceptualization substantively. Marital satisfaction is considered as a marital goal and is defined as: "the degree to which the desires of individuals are fulfilled" (p. 42). Satisfaction can be with the marriage as a whole or with some specific aspect of the marriage situation as with one role function. No matter how it is viewed it is thought to be a continuous phenomenon which is very dynamic with peaks and valleys over the marital cycle.

Marital adjustment is used to label the overall general assessment of the marital experience. This statement reflects the original formulation of the idea by Burgess and Cottrell (1936). According to Burr (1973), the term lacks meaning because it is too complex to usefully operationalize and therefore difficult to use in theoretical formulations. The term happiness is sometimes used to denote the same idea as adjustment and at other times it is used synonymously with satisfaction.

Spanier (1976) in support of the concept defined adjustment as an ever-changing process with a qualitative component which can be evaluated at any point in time on a dimension from well adjusted to maladjusted. Spanier through his work with Cole developed the definition of adjustment as a dynamic process rather than a static state from a synthesis of marital adjustment literature. From this they developed an instrument which could "snapshot" the continuum of adjustment. The scale has four empirically verified components: dyadic satisfaction, dyadic consensus, dyadic cohesion and affectional expression at any point in time. This definition of adjustment as an on-going process throughout marital life was also taken by Peterson (1979) in his study in which one spouse was physically handicapped.

As the current study was an exploratory one in an area where process is important, it would seem appropriate to use this concept of adjustment. There are many factors to be considered throughout the post-injury period which influence the dyad and Spanier's Scale provides an instrument to explore these factors. The Dyadic Adjustment Scale was developed by G.B. Spanier to assess the quality of marriage, it is stated

to be "theoretically grounded, relevant, valid and highly reliable" (Spanier, 1976, p. 15). The total scale reliability is reported as .96 and the assessment of content validity, criteria-related validity, and construct validity appears to indicate that the Dyadic Adjustment Scale does measure the theoretical construct to which it addresses itself. There are four subscales, Dyadic Consensus, Dyadic Cohesion, Dyadic Satisfaction, and Affectional Expression (Spanier, 1979) (Appendix E).

The interviews were hand recorded on the individual schedules as well as audiotape recorded to assist in later analysis.

Analysis of Data

The interview responses were coded according to the role function under study. This was supplemented by data from UAH records.

An individual profile was developed for the husband and the wife and comparison made on the Dyadic Adjustment Scale and subscale scores. The findings were reviewed for process using symbolic interaction concepts and then the research questions were addressed. Each dyad comprised one case study.

Given that a case study approach was used to explore the marital dyad there is a need to comment on some of the ethical dilemmas involved in detailed studies of this type.

The interviewer was aware that the informal setting of the home encourages self-disclosure. The respondents were informed that they could at any time conclude the interview or refuse to answer a question. Though the interviewer did attempt to increase content responses through various techniques, the respondents' attitude to answering was honoured.

The description of each dyad is quite detailed. This was felt necessary in order to have sufficient data to analyze the adjustment process. It was with the full knowledge of the risks of personal and public exposure that the analysis was undertaken. Every attempt to protect the dyad's identification was made while still striving to learn more about the adjustment process.

Summary

An exploratory case study approach was taken to study the impact of the husband's spinal cord lesion on the marital dyad. A depth interview schedule was used to structure the interview and an assessment of the quality of marriage was done using the Dyadic Adjustment Scale. The conceptual framework of symbolic interaction was used to discuss the dynamics of the dyad.

CHAPTER V

STATEMENT OF RESULTS

Each case study will present an individual profile of husband and wife. The husband's profile will include (a) an overview of traumatic injury and medical treatment; (b) a summary of physical and psychosocial status throughout hospitalization; (c) an occupational history and present employment status; (d) a social interactional history and present status statement; and (e) the client's view of sexual functioning and satisfaction.

The wife's profile will include (a) a description of interview behaviour and response to interviewer; (b) the wife's account of the active treatment period; (c) her occupational and financial concerns; and (d) the wife's description of the marital relationship before injury and post-injury changes - psychosocial and sexual activities. The individual numbers of items on the interview schedule are cited as appropriate for the reader's convenience and they can be found in Appendix C.

The dyad will be discussed using the Dyad Adjustment Scale and interview responses.

TO THE READER: The material in the following pages is of a sensitive and personal nature. It was given in confidence and it is expected that the reader will honour this commitment.

DYAD ONE MR. AND MRS. A

Mr. A Hospitalization

Medical overview. Mr. A was born on November 28, 1949 and is the youngest of seven children of a "close" family. On July 29, 1976, he sustained a cervical lesion between the sixth and seventh vertebrae (C 6-7) when he dove into shallow water. He was at a provincial park with his wife and members of his family. He was taken immediately to a small rural hospital where sandbags were applied to keep his head steady. After two hours, he was taken to the University of Alberta Hospital in Edmonton where he was given a tracheotomy and, following emergency cervical surgery, he was placed in skull tongs. Mr. A remained in the Intensive Care Unit (ICU) for 3 weeks and then once his condition stabilized he was moved to Nursing Station 54. Eventually he was transferred, on September 2, 1976, to the Aberhart Hospital which houses the University of Alberta Hospital rehabilitation unit. He was diagnosed as having a partial transection of the spinal cord at C 6-7, resulting in quadriplegia with some sensation and pressure sense and no hot/cold discrimination. Mr. A. was discharged from the University of Alberta Hospital on April 11, 1977. He went to Vancouver to the G.F. Strong Rehabilitation Institute (GFS) for approximately 3 months and then was re-admitted to University of Alberta Hospital as an outpatient on July 21, 1977 and discharged at the end of August 1977.

Physical and psychosocial status. Mr. A's functional ability was described on April 11, 1977 in a physician's discharge summary as being:

independent in bed activities, grooming, washing, feeding, upper and lower extremity dressing, transfers on and off bed and toilet but requires some assistance in washing perineum lower extremities and back, in putting on shoes or slippers and transferring into and out of tub and car. He is also independent on condom and leg bag applications.

There was no mention of emotional status in the official discharge summary.

From reviewing Mr. A's hospital chart and rehabilitation notes, there are several indicators of changes in affect and response to treatment. Early nursing notes (July and August 1976) frequently use the word "cheerful" to describe Mr. A's mood with occasional notes stating "he appears depressed" or "was anxious".

A psychiatrist's assessment on September 9, 1976 found a normal mental status describing the patient as having been "motor oriented" and expecting that there would be a reaction "later on to his disability which entails physically an inactive life." This was supported at this time by a report of the unit's psychologist. The report stated that the dyad had not "accepted the physical findings reported to them and still assume that Mr. A will walk again." This was also documented by the social worker on September 18, 1976 and again later on October 7, 1976, following a family conference.

The psychologist describes Mr. A as having "excellent motivation". From September to December, there was a high level of activity in physical and occupational therapy resulting in increased functional independence. On November 18, 1976, Mr. A passed a trade estimator

examination with a 70% average and in December began the driver training program for hand controlled vehicles.

In late November, the nursing notes indicated some "pensive periods" but otherwise he was "cheerful". The psychologist on December 6 noted that the patient "appears more depressed, or at least more willing to admit to depression." He also states that Mr. A appears to be "attempting to cope with the situation by becoming more demanding." He went on to say that this was affecting the marital relationship and a series of meetings was to be held. On January 11, 1977, the psychologist notes that Mr. and Mrs. A say things are better but "from observation, there is [a] doubt if there has been any significant changes." Further difficulties were anticipated.

Mr. A reported on interview that he withdrew at times and tried not to show his feelings. "I wasn't myself within myself." He attended programs but cried at night and found the most emotional support from another patient; this individual was credible because he had been through the same situation. Mr. A stated he did not feel comfortable with most staff members; however, his physiotherapist and the psychologist in particular were the two people to whom he could relate.

In February, the physiotherapist noted that Mr. A is "frightened" over how he will manage at home and of what will become of him. At this time, discharge planning and home programming had begun. The nursing notes also stated that he was anxious over discharge. The staff felt that this was normal for this stage of the rehabilitation process.

In early March, Mr. A accompanied by his wife, went to Vancouver and visited the G.F. Strong Rehabilitation Institute (GFS). Upon his return

to the University of Alberta Hospital, he stated he wished to be transferred to GFS as he felt he could make more progress there and that they had more to offer vocationally. A physiotherapy note at this time says that the problem is that Mr. A is lazy and is not taking advantage of the resources available to him or taking responsibility for himself. During the interview, Mr. A stated that one of the things that influenced his decision to go to Vancouver was he was not getting on with "his new therapist".

During his hospitalization, Mr. A was visited almost daily by members of his family, his wife, her family and friends. There is also mention of the elders of the church visiting.

In summary, throughout Mr. A's hospitalization, there is mention of changes in mood and behaviour indicative of a reaction to his spinal cord injury. None of his responses though appeared to be so serious that he was clinically diagnosed as depressed or called a difficult patient. The area of concern noted was within the marital dyad where problems were arising. Upon discharge, Mr. A was independent in most activities of daily living requiring only assistance with tub, and car transfers and with his catheter.

As Breadwinner

Occupational history and present employment status. At the time of his injury, Mr. A was a full-time trade apprentice with the City of Edmonton. He had begun as a labourer but fought to get into the trade program to up-grade himself. His ultimate goal was to be a high school

vocational teacher. His salary at the time of injury was adequate for the family's needs and the possibility for advancement was good.

Mr. A had gone to grade 12 but did not complete all his courses. After his disability, he thought about academic upgrading and went to NAIT to be interviewed for the business administration program. He was convinced by the counsellor that it would be too difficult with a SCI to keep up with the work and so he did not pursue it.

Although Mr. A is still employed by the City, his new position as a Clerk II was not offered to him automatically. Within the hospital records, there is reference to him being "reassured by union and employer" that a job would be available post discharge. This was not the case and he spent approximately eight months without employment. He states it took a constant effort on his part to convince his employer that he could work. Mrs. A relates the same events but says that she was actively involved in convincing the City to rehire her husband. It was she and her sister who called and nagged the City and who encouraged Mr. A to keep on looking: "there was a lot of fighting to be done."

During this period of unemployment, Mr. A also went to Canada Manpower and Social Services to seek assistance in finding employment. He supported himself and his family with money received from insurance premiums, sick pay and union donations. He also received the Alberta Government Disability Pension.

Mr. A was first given a job through the City personnel department as a fare attendant. After two years he moved to his current position of Clerk II which involved processing work orders. Mr. A goes to work via a public transportation system for disabled persons (Item 81b) as there are

no parking facilities for his own car. The building is not independently accessible which is also a problem. His DATS¹ fare is paid by the City Welfare fund. This fund also purchased the two wheelchairs he has required.

Problems in working (Item 81a) are architectural, difficulty in performing some of the required duties (i.e. filing cabinets are too high), and a conflict with his boss. Mr. A feels that his boss is uncomfortable with his presence and does not want him there. Mr. A says (Item 84) he is a little unsatisfied about his present position citing that his pay is too low and that the restricted environment of the building are his major concerns. The things he considers good about the job are the fringe benefits, the responsibility and the opportunity for advancement. He was about to be interviewed for a supervisor's position (Item 82).

Mr. A works a full 37.5 hour week and is paid approximately \$14,000.00 a year which is not adequate to support his wife and three sons, ages ten, seven and five. In 1978, Mrs. A and her sister started an industrial janitorial service as it was necessary to supplement Mr. A's earning. The business was very successful and by 1980 they had ten employees.

In summary, after some difficulties in getting the City of Edmonton to rehire him, Mr. A is now employed as a clerk. Although this is

¹ DATS. Disabled Adults Transit System, a public transportation system supplied by the City of Edmonton.

fulltime employment, it is not adequate to maintain the family's lifestyle. As a consequence, Mrs. A has begun her own business which is very successful and has become the family's primary income source. Mr. A hopes eventually to find another position within the City so he won't lose his fringe benefits and seniority. No such position has been available to date.

As Social Companion

Social interactional history. Mr. A's interests and activities prior to injury were "physically oriented". He was considered a good athlete, having won many awards. This is reflected in his present build of well developed musculature around shoulder girdle, upper arms, neck, back and chest. He owned his own speedboat and camper and the family was very active in the outdoors.

Mr. and Mrs. A socialized with his friends who were also involved in many of his sporting activities. Mr. and Mrs. A went to parties, danced and he considered them to be very active. Friends frequently dropped by their home which was considered a meeting place.

Though Mr. and Mrs. A had three boys of their own they also had looked after foster children for four years. The hospital records note that they wanted to have more children but were unable to because of a blood incompatibility. At the time of injury, they had two foster children and the social worker's report states that "having foster children seems to be a vocation" to them.

Mr. and Mrs. A own their own home and he went there upon being discharged. Home visits began on September 19, 1976 with a day pass. The first overnight visit took place on September 25, 1976 and his first weekend pass was on September 30, 1976. From that time on, Mr. A went home almost every weekend. At Christmas he had a four-day pass and in early March he went to Vancouver with his wife.

Sometime after Mr. A's injury, his parents moved into the basement of his home. Mr. A's mother (available at first interview) said they wanted to be of assistance and be close by if needed. They stayed there approximately six months.

At the time of the interview, Mr. A was living with his parents in a townhouse which was within walking distance of his house. Mrs. A and the children are living in the house. Two of his boys were visiting him during the 1st interview. They were very responsive to him and openly affectionate (brief five minute observation).

Mr. A was asked on the LSQ to state the number of hours per week he usually spent engaged in the nine listed activities: listening or watching TV and radio, reading, doing hobbies, visiting in the home, visiting away from home, attending sports events, doing group activities, playing cards, listening to talking books. An "other" category was also listed to allow personal responses. Mr. A responded to only two items; TV or radio, ten hours and reading, five hours (he was still with his wife). At that time he said he had visitors at home approximately one to three times per month and that he got away from home for social or entertainment purposes at least one to two times per week. Mr. A is

independent in transportation as he has a van fitted with an automatic lift and hand controls.

During the first six months to one year post discharge (Items 140, 140A, 141 and 142), Mr. A stated that only one or two friends came to visit and this would be about every two weeks. He said he wasn't ready to see people, but even more important he didn't want to see them. He went out approximately six to eight times a month but he "felt very uncomfortable as he thought people were looking at him and they were." He and his wife attended most of the social events at the Association of Canadian Travellers Centre. They met many new people some of whom were disabled.

At the time of the interview, Mr. A stated he still goes out approximately six to eight times per month but because of his present circumstances (his separation and pending divorce) that he "didn't feel like it now" (Items 143, 143a, 144, 145, 146). He socializes with an old childhood friend who is able-bodied and another friend who he describes as a "walking quad". He stated that he would like to return to church functions, more for socialization and companionship than religious need, but wasn't sure this would be possible. Mr. A is a member of the Mormon Church but only became one after his injury. His wife has been a member for many years. He stated that he thought he might be "excommunicated" once the divorce was finalized.

From the observation made while in Mr. A's parents' home, it was noted that his mother is quite doting and quick to initiate anything he might need. She is verbally spontaneous and curious and had to be asked tactfully to leave the interview situation. Mr. A's father remained in

the living room watching television. Mr. A was careful with the wording of his responses when his mother was around. He was particularly sensitive to his lack of privacy and rated this as the thing that frustrated him most (Item 174). It is his intention to look for his own place as soon as his marital situation was stabilized. When asked how he ventilated his frustration, he stated he would lie on his stomach and "pound the bed" or get into his van and "drive at high speed and go".

In summary, Mr. A does not engage in the same type of activities he did prior to his injury. He now spends his time in sedentary activities, sees fewer people and has changed his living arrangements. He is now separated from his wife.

As Sexual Partner

Sexual function. In the fall of 1979, Mr. A responded to the LSQ and stated that with his sex life, he was "somewhat satisfied" on a five point scale with the rating being 1) very satisfied; 2) somewhat satisfied; 3) neutral; 4) somewhat dissatisfied; and 5) very dissatisfied. At the time of the last interview in September 1980, Mr. A was very dissatisfied with his sex life because of a lack of a partner and little privacy (Item 163). Mr. and Mrs. A were now separated with a divorce pending, and Mr. A stated a "major contributing factor" to the marriage breakup was their "sexual relationship problems". When asked if he thought their problems could have been overcome, he said "No, knowing my wife, no. If it could have been, I would have been willing to work it out."

Mr. and Mrs. A did attend a Sexual Attitude Reassessment (SAR) workshop in March 1977. He reported that following that they were "very open" but it didn't last. He stated his wife could not accept the difference in their sexual activity and couldn't accept him as he was now. In response to the question "What changes, if any, have you made in the nature of your sexual activities since your injury" (Item 162), Mr. A reported (c) reduced frequency of intercourse; (e) use of mechanical aids (vibrators, dildo, etc.) and (g) alternative methods of stimulation (masturbation, oral sex, etc.). He also reported in response to Item 161 "since your SCI, has the importance of sex changed in your life?", that it has become (5) very important adding "but in a different way, more aware of partner's satisfaction." "I wasn't satisfying her the way she had been satisfied." (With Mr. A's type of lesion he is capable of a reflexive erection and has some deep sensation. He has bowel and bladder control via condom drainage and a bowel routine). He stated that he and his wife had a very satisfactory sex life before his injury and sexually were very active having intercourse at least twice a week. There is a report in the hospital notes stating early in the marriage, Mr. A sought help for impotency and it disappeared after treatment with a "placebo".

Throughout the interview, Mr. A kept returning to the problem of his wife's lack of acceptance of his disability and her dissatisfaction with their sexual activity. He stated that his wife complained that he never held her, yet she never made the effort to move to him. He described some improvement after the counselling sessions but later she "would destroy the mood or not help if [an] erection was not coming."

When asked for the reasons that he was not currently sexually active (Item 163), he responded that he lacked privacy (c) and his partner lacked interest (f). When asked to note the single most important reason of those noted he stated (f).

In response to Item 174, "what are your greatest sources of frustration", he lists "sexual deprivation" as the second most frustrating situation of the seven areas listed: loneliness, physical limitations, lack of money, poor health, boredom, sexual deprivation, living arrangements or lack of privacy and other. Living arrangements or lack of privacy was first, physical limitations was rated number three and loneliness was four. There were no other notations. When asked if, since his SCI, he had received any helpful sexual advice, information, counselling or training (Item 165), Mr. A stated that the SAR he and his wife attended was the most helpful and that the doctor and physical therapist in hospital were also of assistance.

In response to Item 167, "What changes if any, would you like to make to improve your sex life", he stated "have a partner". Mr. A stated it was very difficult to bring a girl home and tell his mother that she was going to spend the night.

Satisfaction with his body was rated as 3.5 on a 5 point scale with 1) very satisfied, 2) somewhat satisfied, 3) neutral, 4) somewhat dissatisfied, 5) very dissatisfied. He stated that it changed from day to day with "some days o.k. and other days I feel that my belly is very big." At the time of the interview, Mr. A responded that he did like himself and was prepared to start a new life.

In summary, Mr. A is a 31 year old, wheelchair bound, pleasant looking man of athletic build with obvious atrophy to his lower arms and hands. Due to his previous endomorphic build he appears slightly overweight with the characteristic protruding abdomen of the quadriplegic. He spoke openly about his sexuality during the interview except at those times when his mother was present. He appeared relaxed but occasionally became more animated and noticeably distressed when discussing his marital situation. His voice changed to a more harsh tone and he was quite emphatic about his interpretation of his wife's response to his disability and the change in their sex life. Throughout the rest of the interview time, he maintained a smile and a casual manner of delivery. He presented himself as being accepting of his disability and wanting to get on with living.

Mrs. A

Interview situation. Mrs. A presented herself as a tidy, fit young woman (29 years old), somewhat anxious as reflected in her tight body posture and rapid speech. She had good eye contact and an animated facial expression.

As the interview progressed, her posture relaxed but her speech remained rapid with frequent changes in voice tone and at times a noticeable "cracking" in her voice. Mrs. A spoke openly and spontaneously in describing her own feelings and gave a comprehensive interpretation of her husband's feelings and behaviour during the post-injury period. She gave many specific events and behavioural examples to document her position.

Mrs. A's account of the active treatment period. Mrs. A stated that she didn't know what to expect after Mr. A's injury. She was told by a physician that he would never walk again and that the smartest thing she could do was leave. She knew nothing about disabilities let alone a spinal cord injury. "I thought it was temporary. I couldn't believe he would always be like that - there had to be something that could be done." Mrs. A was told that her husband couldn't walk and that he wouldn't have full use of his hands but "what I found out was a lot of other things were missing too."

Mrs. A described Mr. A's first home visit as a "nightmare" and that no one had explained the implications of breaking one's neck. "I was shocked to learn that his bladder didn't work and that he had a catheter but I didn't even realize he had no bowel." On that visit home Mr. A had a bowel "accident" and Mrs. A said that she was so shaken that Mrs. A Senior took over. It wasn't till February 1977 that the Hospital records documented a formal teaching session on bladder care. Mr. A started going home in September.

On her husband's first overnight pass, Mrs. A said it was like looking after a new born baby; having to turn Mr. A every three hours. "No one sat me down and told me what to expect, only you will have to do this and they showed me. It was different doing it at home than just watching in the hospital."

It appears that certain factual information was given to Mrs. A but that it was necessary for her to personally seek some of it out. She received two books from the nursing station on SCI which she and another patient's wife studied. In retrospect they were of little assistance, as

much of the information didn't apply to her husband's case. Mrs. A says she was quite naive and doesn't blame the hospital. "I didn't know who to ask or what to ask about."

Mrs. A stated that the general care was good at the University of Alberta Hospital but she felt that the self-care programming was lacking. It was the G.F. Strong Rehabilitation Institute that taught him to be independent. He couldn't do anything for himself before he went to Vancouver and it was necessary for her to do everything. "I would have to put on his connecting equipment - condoms." When Mrs. A saw her husband shave and dress himself in Vancouver, it gave her hope: "I almost flipped". Till this time she said that she had had little opportunity to see exactly what he was capable of doing.

At the GFS, Mr. A was taught "to do everything for himself including putting on a condom for catheterization." Mrs. A stated that the therapists at the Aberhart were good but the "psychological and self care program was superior at the GFS." The programs were very supportive of her and her husband.

By this time, Mr. A had received his driver's license and Mrs. A had had a boogie van fitted with hand controls and an adapted seat. This she took to Vancouver. She stated that two years later, he wanted something else and she got it for him. "It cost a pile of money, but whatever he wanted, I made sure he had." I felt I was always being tested. He was demanding, he wanted everything, like not now, but right now."

In summary, Mrs. A did not know what to expect as a result of her husband's injury and found the information given her at the University of Alberta Hospital to be of little assistance in coping with his new state

of physical dependence. It was a very traumatic time. His greatest gains in functional independence according to her occurred when he went for treatment at the GFS in Vancouver. It was here that she gained the most understanding of her husband's injury and received the most professional psychological support.

Occupational and financial concerns. Returning Mr. A to the work force was a difficult task (Item 6). Mrs. A stated that it was a disappointing and humiliating time for her husband. During his early convalescence Mr. A was considering academic upgrading but his boss said that with a job waiting for him, why bother. As previously noted, there was no job available when Mr. A was ready to return to work in the fall of 1977.

In January 1978, Mrs. A and her sister began their own janitorial service. She had previously always supplemented the family income by working from the home doing such things as babysitting. When Mr. A had his accident she stopped taking in children. She was just able to look after her own three boys, the house and still go to the hospital daily. When Mr. A returned home and could not be re-employed immediately, it was necessary for her to again generate some revenue. It should be remembered that the family's source of income at this time was sick pay, union donations and eventually a disability pension that Mr. A said paid \$50.00/month/child and \$7 for himself.

Mrs. A stated that she and her sister really fought to get Mr. A a job with the City. It was eventually through the special efforts of a girl in the City personnel department who takes care of disabled people

that he got his first job. "We tried everything to get him into a position where he could feel important."

Mrs. A said that Mr. A was depressed at that time and he did little to help himself. "He was feeling down." If it weren't for her own job, Mrs. A says that she too would have needed help. "It was the thing that kept me sane."

Most of her support at this time came from the discussions with her sister and with her own family. They were concerned about her as she had had a "nervous breakdown" as an adolescent when her parents divorced. She describes herself as acting out at the time and eventually overdosing on some pills. Since then, she has had no further psychiatric care.

Mrs. A stated that during the entire time that Mr. A lived at home she never once slept in. She performed all her old duties and assumed new responsibilities. "I was running 24 hours a day. I'd come home from work in the morning and he would want his hair washed before going to the office." He was even more demanding during the period that he was unemployed. Mr. A refused to do the self-care activities "that he had been taught out there because things [physical layout] weren't the same." After three months, Mrs. A says she told him she had had enough and he could do it himself.

Mrs. A stated that she had to become more independent to take care of everything. "I would say, 'how about helping with the books?' [company's] and he would say, 'you're doing a good job so far, you can do that too.' Everything was mine to do and he despised it." The more the company became successful, the more Mrs. A says her husband withdrew from her.

Before his injury, Mr. and Mrs. A made decisions together, but he had the final say. After her husband's injury, Mrs. A said that she assumed the decision making role because she had to. When she attempted to involve him, he "shuffled off and said just go ahead. He wanted to be involved till I involved him and then he didn't want to. I'd tell him but he wasn't listening."

When asked if finances were a concern, Mrs. A stated that they weren't as her business was doing very well. In fact, she was concerned that now with a divorce pending that she might have to pay Mr. A alimony.

In summary, after approximately eight months of her husband being unemployed, Mrs. A stated she was instrumental in his being re-employed by the City. Prior to his returning to work, Mrs. A formed her own janitorial company to supplement the family income. During this whole period of time, Mrs. A stated she was constantly on the run, taking care of the normal house duties as well as her husband's self care activities. As a result of this situation and her husband's abdication of his responsibilities, she also assumed the responsibility for major decision making.

Marital Relationship Before Injury and Post Injury Changes in Psychosocial and Sexual Activity

Psychosocial activity. Mrs. A described her husband prior to injury as being happy-go-lucky, athletic, perfectionistic and performing at a high standard. He was always first or the best and was very outgoing. He liked to have people around and always wanted to do everything. He

was the life of the party. They did everything together and never went on a holiday or anywhere alone.

Mrs. A stated that her "job" was to ensure that the house was in "good order, spotless, the ironing done, the kids were well kept when he was away, that was my job. My role was the mother's role."

Mr. A looked after all the household maintenance and the yard. "The grass, our yard was like a green carpet - [it] never had a weed ... always perfect. He did it all. He did everything outside the home." They always had people at their home. According to Mrs. A everyone would say "go see the A's". If they weren't at home on the weekends they would be camping. "We just had everything, there was nothing we didn't have." Mrs. A rated her marriage before Mr. A's accident as very happy. "We had a very good marriage."

Following his injury, Mrs. A described her husband as being less energetic, less happy, less sociable, less talkative and harder to get along with. "Everything was negative." He continued to "put self down and I was constantly trying to build him up." He was verbally abusive, he screamed and yelled at the children which he never did before his injury. "They would go to bed crying and I would try to explain how he was feeling." Mrs. A felt that she couldn't do anything right. She was screamed at if she did do something such as cut the grass, "What would the neighbours think" and screamed at if she didn't because nothing was good enough. "There was no happy medium. Everything was my fault, the dripping tap which I couldn't fix, the walls that needed painting. He had standards and they had to be kept."

Once he attempted to hit her. Mrs. A stated that she told him he would never hit her again and if he did she would hit him "doubly". Mr. A was very strong in his upper arms and sometimes would grab Mrs. A "playfully". Mrs. A stated that if he did grab her in the "crook of his arm, I couldn't get loose." Mr. A always said he was just "horsing around" but Mrs. A stated that she thought he did it for spite as a way of dealing with his frustrations.

Mrs. A stated that during the time that he was home that he was "so unhappy in himself I was afraid he would cause damage to himself." He would often say that he felt like taking the car and driving it into the bridge. "I was scared. I really felt at times he would do that." He withdrew and was becoming completely opposite to how he was before the accident.

It was difficult to invite people over more than a week in advance because his mood was unpredictable. Mrs. A stated that people were hesitant to come. Mr. A would either withdraw or become verbally abusive especially toward her. His remarks were snide and insulting.

He wouldn't go out because he would need help and then Mrs. A said that only she could help him. He would demand that she take him up the stairs. "I was frightened the whole time. Once he fell out [of his chair]; missed his chair on a transfer and fell to the floor."

When they did go out she felt she was on display like a doll and that was the only time that he was pleasant towards her. "I had to have the best clothes so I looked good - showed me off to his friends and [in] the meantime he was so mean to me." It was only a paper relationship with Mrs. A telling him "I'm your bloody maid."

In summary, there were definite changes in Mr. A's mood and social behaviour following his SCI. He became depressed, he was verbally and physically abusive and at times withdrew. Friends ceased to call. Despite Mr. A's overt physical threats Mrs. A was concerned about his safety. The change in their marital relationship was also a major concern.

Sexual activity. Mrs. A stated that she and her husband had a very enjoyable sex life prior to Mr. A's injury. It was a very important part of their relationship.

From the time of his first home visit, Mrs. A stated there was a change in Mr. A's expression of affection and sexual interest. "He made no attempt to come near me." He would frequently say "Look, how repulsive I am." Mrs. A said that at these times she would try and build him up realising that he was "so down on himself".

During the early home visits, Mrs. A never "honestly realised that [we] wouldn't be able to have a man-lady relationship - intercourse would be different." In retrospect attending the Sexual Attitude Reassessment Workshop was helpful but at that time, Mrs. A said she still didn't fully understand the extensiveness of her husband's disability. "I wasn't clued in. I didn't know what applied to him."

When asked if some of the negative changes, which were a result of Mr. A's disability, could have been avoided, Mrs. A said "No". "He would never tell the doctor the truth [what was bothering him] - that he felt less of a person. As a consequence he never really dealt with his

feelings." Mrs. A said she told her husband that she felt very unloved and that she needed something back from him.

Mrs. A stated that at that time she could almost accept that there would be no sex in their life. During his hospitalization she had told herself "if it can't be, then accept it - he has all these other qualities. I knew I'd really miss it but he was my husband." Later the test results from the GFS indicated that Mr. A could have an erection and maintain it. When he arrived home he couldn't and Mrs. A felt that it was due to his mental state.

If they tried any sexual activity "it was a nightmare", as Mr. A would "put himself down." Mrs. A said that she was "always building him up, up, up and there was nothing nice [said] about me." When asked if Mr. A was willing to experiment, Mrs. A said he was not. He would say, "this is not going to be the same."

In one desperate act, Mrs. A brought home some devices to assist in prolonging an erection. When she presented him with them he asked if it was a joke. Mrs. A told him it started out that way but it wasn't. Mr. A "fooled around" with them approximately twice stating if he had to do all of that "it had to be the same." Mrs. A said that at that point he returned to saying how repulsive he was and that by this time "I got fed up and I began to think so too. If he had just said something positive, I would have responded. I know the type of person I am." When asked if she had considered sexual options outside the marriage, Mrs. A stated that because of her "religions beliefs and what have you" that was not for her.

In approximately January, 1980 they went for sexual counselling. Mrs. A said that in retrospect it was probably helpful but in the first session she was "completely put down for expecting sex as if that was the main problem when it wasn't. It was because he had changed so drastically." Later sessions were more beneficial and the therapist acknowledged his lack of objectivity when Mrs. A confronted him.

Mrs. A said that the main problem was not sex. She "could easily settle for an oral type relationship or a relationship," but it was necessary for something to be there. Mrs. A recounted that she was "bending over backwards" to do things she had never done in her life but to whom could she turn to feel important?

Following the sexual counselling sessions, Mrs. A said Mr. A tried "for about a week, then he shut himself off from me - nothing to do with me." At that point she told him he needed help and he said he knew, but nothing could help.

It was then that Mrs. A realised that she would have to explore the reasons for remaining in the marriage. Was it a desire to be needed, was it love or was she just clinging to anything?

Mrs. A said that on two occasions her husband had offered her to another man. The first time it was to Mrs. A's brother-in-law and the second time it was to a close personal friend of the couple's who Mr. A described as a "walking quad." He had just returned from the para-olympics in Holland where he had been a medalist in swimming.

It was shortly after this that Mrs. A attended a family wedding on the coast and decided that she could no longer stay in the marriage. When they finally made the decision to separate, Mrs. A said she asked

her husband to tell her why he had given up on things and why he refused her sex. Mr. A stated that he was hurting. Mrs. A then said that he knew that in their marriage prior to his injury that sex was very important to her and if he took that away from her, she'd be hurting too. He said, "something like that."

In summary though there was information available on sexual ability following a SCI, it appears that there was inability on the part of Mr. & Mrs. A to attain a new mutually satisfactory sexual relationship.

Dyadic Adjustment

As previously stated the Dyadic Adjustment Scale was used to assess the quality of marriages. It is comprised of a 32 item scale which is suggested can be re-organized into four empirically verified components of dyadic adjustment: affectional expression, dyadic consensus, dyadic cohesion and dyadic satisfaction. These areas represent the subscales. Table I lists the 32 variables numbered according to their position in the scale and states their subscale affiliation.

Marital dyad pre-injury. Mr. A's total Dyadic Adjustment score was 123 out of a possible 151 for his marriage prior to injury. Mrs. A's total Dyadic Adjustment score for the same period was 117. All four subscales, affectional expression, dyadic consensus, dyadic cohesion and dyadic satisfaction, had similar scores for Mr. & Mrs. A. Table II summarizes the pre-injury scores Mr. & Mrs. A attained on the Dyadic Adjustment Scale and its subscales.

When asked to rate their marriage before Mr. A's injury, both stated that it was extremely happy. There was 1 scale point higher perception

TABLE I

Dyadic Adjustment Variables with Subscale Notations

VARIABLE NUMBER	SUBSCALE
1. Handling family finances	Dyadic Consensus
2. Matters of recreation	Dyadic Consensus
3. Religious matters	Dyadic Consensus
4. Demonstrations of affection	Affectional Expression
5. Friends	Dyadic Consensus
6. Sex relations	Affectional Expression
7. Conventionality (correct or proper behaviour)	Dyadic Consensus
8. Philosophy of life	Dyadic Consensus
9. Ways of dealing with parents or in-laws	Dyadic Consensus
10. Aims, goals, and things believed important	Dyadic Consensus
11. Amount of time spent together	Dyadic Consensus
12. Making major decisions	Dyadic Consensus
13. Housing tasks	Dyadic Consensus
14. Leisure time interests and activities	Dyadic Consensus
15. Career decisions	Dyadic Consensus
16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	Dyadic Satisfaction
17. How often do you or your mate leave the house after a fight?	Dyadic Satisfaction
18. In general, how often do you think that things between you and your partner are going well?	Dyadic Satisfaction
19. Do you confide in your mate?	Dyadic Satisfaction
20. Do you ever regret that you married? (or lived together)	Dyadic Satisfaction
21. How often do you and your partner quarrel?	Dyadic Satisfaction
22. How often do you and your mate "get on each other's nerves?"	Dyadic Satisfaction
23. Do you kiss your mate?	Dyadic Satisfaction
24. Do you and your mate engage in outside interests together?	Dyadic Satisfaction
25. Have a stimulating exchange of ideas	Dyadic Cohesion
26. Laugh together	Dyadic Cohesion
27. Calmly discuss something	Dyadic Cohesion
28. Work together on a project	Dyadic Cohesion
29. Being too tired for sex	Affectional Expression
30. Not showing love	Affectional Expression
31. Happiness in your relationship	Dyadic Satisfaction
32. Feeling about the future of your relationship	Dyadic Satisfaction

TABLE II

Married Respondents' Dyadic Adjustment Scale and
Subscale Means as Compared to Pre-Injury Scores
for Dyad A

Scale	Spanier's Married Respondents' Mean Scores	Highest Possible Score	Mr. A	Mrs. A
Affectional Expression	9.0	12	12	11
Dyadic Consensus Subscale	57.9	65	52	48
Dyadic Cohesion Subscale	13.4	24	14	16
Dyadic Satisfaction Subscale	40.5	50	45	42
DYADIC ADJUSTMENT	114.8	151	123	117
	N=218			

on the amount of agreement for Mr. A and on major decision making, financial, aims and goals and complete agreement on career decisions and household tasks. They had no financial worries. They owned their own home, a car, a camper and a speed boat. Mr. A was the primary breadwinner with Mrs. A supplementing the family's income by looking after children in the home. As a trade apprentice, Mr. A looked forward to a steady rise in income once he received his journeyman's papers.

Socially, they were very active agreeing most of the time on friends but having some disagreement (1 scale point) on recreation and leisure time interests and activities, and 4 scale points on amount of time spent working on a project together. Mr. A said they did it less than once a month but Mrs. A said they did it more than once a day. Similarly for the amount of time spent together, Mr. A said they always agreed and Mrs. A said they occasionally disagreed, a 2 scale point difference. They agreed totally that they confided in one another, and most of the time felt that things between them were going well.

Sexually, they always agreed and demonstrated a high degree of affection toward one another. Neither of them indicated that "being too tired for sex" or "not showing love" was a problem, and they kissed almost daily.

In summary, prior to Mr. A's injury, Mr. & Mrs. A had a high degree of dyadic adjustment as measured by the Dyadic Adjustment Scale and felt that their marriage was extremely happy and that they "would go to almost any length" to see it succeed. Neither of them ever regretted their

marriage though occasionally they got on each other's nerves and quarelled.

Marital dyad post-injury. Mr. A's post-injury Dyadic Adjustment Scale score was 73 and Mrs. A scored 43. This was a 33% decrease in the Dyadic Adjustment score for Mr. A when compared with his score for his pre-injury relationship and a 55% decrease in the Dyadic Adjustment score for Mrs. A when compared with her score for the same period. Table III summarizes the post-injury scores Mr. & Mrs. A attained on the Dyadic Adjustment Scale and its subscale.

For Mr. A the range of the subscale scores was 2-41 representing a 83% to 8% decrease, in previously attained scores. Mrs. A's post-injury subscale score range was 0-26 representing a 92% to 34% decrease in previously attained scores. (Percentage scores have been calculated as raw score percents of highest score attainable and difference calculated between pre and post raw score percentages as noted).

Both Mr. & Mrs. A rated their marriage post-injury as extremely unhappy, with the greatest discrepancy in score change between Mr. & Mrs. A occurring on the dyadic cohesion subscale. Mr. A's subscale score of 12 represented a 8% score decrease and Mrs. A's score of 6 represented a 42% score decrease resulting in a 25 percentage point spread, when previously they only had a 9 percentage point spread.

The greatest decrease in subscale scores for Mr. & Mrs. A occurred on the affectional expression subscale; Mr. A had a 83% decrease and Mrs. A a 92% decrease resulting in a 17 percentage point scale spread. The dyadic satisfaction subscale had the next greatest decrease in score by both Mr. & Mrs. A. Mr. A had a 54% decrease and Mrs. A had a 62%

TABLE III

Married Respondents' Dyadic Adjustment Scale and
Subscale Means as Compared to Post-Injury Scores
for Dyad A

Scale	Spanier's Married Respondents' Mean Scores	Highest Possible Score	Mr. A	Mrs. A
Affectional Expression	9.0	12	2	0
Dyadic Consensus Subscale	57.9	65	41	26
Dyadic Cohesion Subscale	13.4	24	12	6
Dyadic Satisfaction Subscale	40.5	50	18	11
DYADIC ADJUSTMENT	114.8	151	73	43
	N=218			

decrease resulting in a 14 percentage point spread between their subscale scores, when previously there was only 6.

The dyadic cohesion and the dyadic consensus subscales reversed position for Mr. & Mrs. A. Mr. A had a 17% decrease in the dyadic consensus subscale while Mrs. A had a 34% decrease in score resulting in a 23 percentage point scale spread. The dyadic cohesion subscale has already been reported.

There was no change in agreement between Mr. & Mrs. A on finances and career decisions, but the latter dropped 1 scale point for each. There was an increase in disagreement over making major decisions, Mr. A remained the same and Mrs. A's score decreased 3 scale points. Aims and goals decreased by 3 scale points for Mr. A and 1 scale point for Mrs. A. The perception of agreement on household tasks went from always agree to frequently disagree by Mr. A (3 scale point decrease), to almost always disagree by Mrs. A (4 scale point decrease).

The greatest change in agreement within any of the subscales occurred in cohesion on the amount of time they spent together engaged in outside activity. Mr. A felt that they now spent more time together and Mrs. A felt that now they never spent any time together.

In other areas of social interaction such as recreation, leisure time interests and activities, and friends, an increase in disagreement was also noted. There was less agreement over the amount they confided in one another and there was agreement that things were not going as well between them and that they hardly ever worked on a project together.

Sexually, there was agreement that their relationship had seriously deteriorated as had the demonstration of affection within the dyad. As

previously stated the affectional expression subscale had the greatest decrease in score of all the subscales for both Mr. & Mrs. A, with all items decreasing a minimum of 4 scale points where applicable.² There was no change in the rating for the frequency of kissing, it remained with 1 scale point difference with Mr. A saying every day and Mrs. A saying almost every day.

Both Mr. & Mrs. A rated their marriage as extremely unhappy, yet neither of them changed their view of never regretting that they married.

In summary, there has been a dramatic change between the Dyadic Adjustment scores assessing the quality of marriage before Mr. A's injury and after. From previously rating their marriage as extremely happy, Mr. & Mrs. A now rate their marriage as extremely unhappy and that there is nothing more that either of them can do to make it succeed.

DYAD TWO MR. AND MRS. B

Mr. B Hospitalization

Medical overview.³ Mr. B was born in Europe on October 6th, 1934. He came to Canada in 1956. He has one brother in Edmonton with the rest of his family members still in Europe.

² See Appendix D for scoring of items.

³ All data were taken from hospital records, and LSQ and the interview as manually recorded by interviewer. Taping was not permitted by Mr. and Mrs. B.

On March 2, 1976, while working on a offshore rig, Mr. B fell 20 feet to the platform below. He remained on the platform for some five hours till a tugboat was able to take him to the closest island. The journey took six hours: Mr. B had had no treatment till he was airlifted to a Shell Oil Hospital which was near. Here he was told he had a "pinched nerve" as well as his obvious injuries. March 19, over two weeks from the time of his injury he was informed that he had a "fractured back." He also sustained multiple cuts, bruises and a compound fracture of his upper arm and the distal end of the radius of his right extremity. When asked how he felt immediately after his injury, Mr. B stated he "wanted to be alone and turned and faced the wall" (Item 171).

Since he was a Canadian and had been hired from Edmonton, it was decided to airlift him to the University of Alberta Hospital for further treatment. He was admitted to the hospital on March 21, 1976.

On March 25, 1976 he underwent surgery to reduce his right forearm fracture and release his carpal tunnel syndrome. On May 25, 1976, he had exploratory surgery of his right upper arm because of increased pain.

Mr. B was diagnosed as having a partial transection of his spinal cord at the first lumbar vertebrae (L1) resulting in paraplegia. He was transferred to the Aberhart Hospital on March 31, 1976 for more intensive rehabilitation and was discharged on August 3, 1976 with physical and occupational therapy to be continued on "outpatient" status.

On October 4, 1978 he had a coccygectomy to relieve the intense and constant pain he had. There were no complications and he was discharged on October 20, 1978.

Physical and psychosocial status. Mr. B had a low spinal cord injury (L1) which should not affect hand function; but because of the severe injury to his right arm and wrist area (distal end of radius) he had residual loss of grip, strength and range. He is capable of walking, but is unstable without using a cane or furniture in the room for assistance. On smooth surfaces with few obstructions he is capable of independent ambulation: Mr. B is a "walking paraplegic." He has shoe braces but prefers to wear heavy well supporting boots.

From Mr. B's responses to the LSQ he is independent in eating, dressing, personal hygiene, bowel program. He is partially dependent in his catheter care and putting on medical support stockings. The latter are very important in assisting venous return as he has severe atrophy of all muscle groups in the lower extremities. Mr. B stated he had constant "cramps," spasm in his hamstring muscles, and "no calf muscles and my toes are curled for balance." He is on a number of medications to prevent bladder infections, to reduce muscle-spasm and to relieve pain.

A letter from his attending physician to a lawyer noted Mr. B's permanent reduction in the functional use of his right hand and arm and the severe impairment of bladder and bowel function. The latter is a direct result of the level of Mr. B's lesion L-1 which produces disruption in nerve conduction in the descending tracts as well as direct interruption of the reflex arc. In response to how he felt having to depend on other people to do things for him, he said he was "resentful of dependency and very uncomfortable. It was no good." He had previously never had to ask for anything (Item 30).

The nursing notes and rehabilitation records have limited documentation of changes in Mr. B's mood and behaviour during the hospitalization period. Early nursing notes state Mr. B "was talking cheerfully, appears to be in good spirits." On April 1, 1976, Mr. B is described as "apprehensive of returning [home] and [distress about] loss of bladder and bowel." Later on April 15 there are notes indicating he appeared less apprehensive and "remains in superficial good spirits but some symptoms of anxiety." On April 22 he was up walking and his "spirits [have] improved." From the end of April through to his discharge in August, there continued to be descriptions of affective disturbances over his concern of bowel and bladder dysfunction: "Upset, he didn't feel a thing [incontinent]; Upset about condom coming off when walking and lack of bowel and bladder control...."

On June 3, the nursing notes said "extremely depressed this week; some mention of suicide, psychiatric consultation sent. Wife has not visited this week and [he] is not certain about weekend pass - family problems? Discouraged re: bladder control; sleeplessness."

The psychiatrist's report of June 7 states "patient made it clear he had no need for psychiatric advice; he fell on his back not his head. His attitude seems to be one of waiting to see what happens." Mr. B denied any social or personal accident-related problems with his wife. He described Mrs. B as being very self-sustaining and felt she could cope without any outside help. There were no further consultations documented and this is confirmed on the August 30 discharge summary. There is only one official social work report (May 4, 1976), which was a social history with one reference to his affect. "He appears to be happier [now] with

the moral support of the family." Mr. B's most frequent visitor was his wife and then his brother and sister-in-law.

There are few references to interaction with other patients. At the time of the interview Mr. B said he did not spend much time on the ward talking with other patients. He could walk and was determined to improve so he spent as much time as he could in "therapy" and going up and down the halls. He frequently had extended weekend passes.

From early June till early August, Mr. B was very active in his rehabilitation program and with going home on weekend passes. It is not till August 5 that another change appears. Mr. B is described as having "fever, shaking and rigors. Pyuria with significant growth of *E. coli* in urine." (The latter is a common infecting organism in urinary tract disorders). He was described as "generally miserable with increased dizziness." He was later noted to be "very discouraged re: bladder condition."

Throughout the interview Mr. B expressed his annoyance with the manner in which staff members addressed him. "They never told me the truth, it could be worse. Don't tell me it could be worse - give me the answers, no false hopes" (Item 11). He didn't believe what the staff told him. He described himself as "depressed most of the time, wondering why it had happened." He stated he was mentally poorly prepared for leaving the hospital (Item 21). It was Mr. B's interpretation that they [staff] wanted people out and that "they should have admitted that there would be no recovery...so I went home."

He was visibly angry and kept bringing up examples of events in which he had to give the staff directions (placement of call cord in toilet

area, not being told about an indwelling catheter) or when he wanted to have concrete information and didn't get it. He felt the staff were negligent in not giving him the information. He wanted a list of firms, names and addresses, where he could buy catheter supplies and supportive stockings. It was a waste of his time to run around (Items 29, 32, 184). He also resented needing to actually go to the doctor for a prescription and having to pay full prices at the drug store for items such as condoms.

Mr. B's manner of interaction was brisk but descriptive. He was bitter about his injury but clearly outlined a methodical and comprehensive plan which he intended to follow in future years; one that he felt was the best for him and ultimately for his family.

In summary, throughout Mr. B's hospitalization, changes in mood or behaviour are associated with references to bowel and bladder dysfunction. Even though there is one reference to suicidal ideation, he made it quite clear to the staff that he only desired assistance for his physical disorders and any other type of therapy was not needed. From the absence of further consultations for psychological and social work services, it appears that no further contact was made by professionals in these areas. Upon discharge, Mr. B was ambulatory with assistance, independent in activities of daily living. The severe functional loss in his right hand and forearm made it necessary for him to have assistance with changing his catheter.

As Breadwinner

Occupational history and present employment status. At the time of his injury Mr. B was a rig supervisor and functioned as chief engineer. He had been hired as a rig mechanic but because of skills and experience he was soon supervising all mechanical areas and spent a great deal of time flying from rig to rig. He worked 12 hour shifts but was on call 24 hours a day. The work schedule was two weeks on duty and one week off duty. His income (1976) was in excess of \$20,000.00 per year plus benefits and foreigner employment status (Items 44, 106, 107, 108, 109, 110).

He began working on oil rigs in 1970; previously he had been employed as a heavy duty mechanic supervisor. From 1970 to 1972, he worked on land rigs and then in 1972 he went overseas which was the beginning of his offshore experience (Items 112, 113, 121, 122).

Mr. B stated that problems with the job were the long hours, isolation and occasionally the weather, but that the good things about the job more than compensated for them. He was "independent and free; it wasn't a treadmill - everyday there was a new thing; the money was good and he could travel" (Items 115, 116, 117). He stated in response to a question on job satisfaction (Item 118) that he was extremely satisfied with his job and would have continued had it not been for his accident (Items 119, 120).

Mr. B was educated in Europe. After completing high school, he received his journeyman's papers as a precision mechanic (1951) and in low voltage electronics (1955). At the present time he is officially unemployed and he does not see himself ever returning to the field in any

capacity (Item 50). The interview explored possible job alternatives in which he could use his knowledge and experience in the field advantageously. Mr. B stated quite strongly that he couldn't work (Item 35). Physically his "tolerance was low and [he] couldn't do eight hour shifts and [he] had 'accidents'. People take advantage of you" [when you are handicapped].

Immediately after his accident Mr. B thought he would go to Canada and be back in three months "just a pinched nerve" but following his discharge from University of Alberta Hospital he never expected to return to work "my hand is gone and my back is broken" (Items 24, 43).

The hospital records have a note that Mr. B's employers wished to keep him on staff for a supervisory position. On the LSQ Mr. B stated that his main source of support was from insurance benefits and then his own earnings. Before leaving hospital Mr. B obtained a lawyer and began investigating if he would take legal proceedings against his employer on the ground that he received "inadequate initial medical care."

During his hospitalization and up to the fall of 1977 all medical and living expenses were paid by Mr. B's employer. He was receiving approximately \$1,200.00 per month. When he initiated the suit all benefits and payments stopped. Because of his foreign employment status Mr. B had only Alberta health care coverage and no personal auxilliary insurance plan. He was forced to use his savings, approximately \$20,000.00 to sustain himself and his family. In June 1977, he went on welfare and received benefits till February 1978 when he obtained an out of court settlement from his previous employer.

Mr. B stated he felt "terrible" about receiving assistance but he had no choice. It was either "starve or go to prison" [rob a bank]. He said he "tried to get the woman to go to work but she couldn't get a job. She had the children to look after and couldn't drive" (Items 133, 134, 135). When asked at the latter part of the interview "What do you consider to be the most important thing you've done since your injury?" (Item 168), he responded "getting off welfare."

Mr. B did not explicitly state the amount of his cash settlement, but given his earning potential, his previous salary, and his present standard of living it must have been substantial.

On the LSQ, he stated his annual income was over \$10,000.00. He has a modest house in the city, which is filled with furnishings from the South Pacific. He purchased a quarter section of land near Gibbens and is presently building a large house on it. This project has now become his full time occupation. He is the general contractor and does as much of the actual construction that his physical state will allow. He had just completed all the wiring working at his own pace and calling in assistance as required. This usually came from Mrs. B's family.

He leases his land out for a percentage share of the earnings and presently has six cows and intends to buy more. He has a travel trailer approximately 20 feet long, a truck, numerous pieces of moderately heavy equipment and his wife has a car (obtained driver's license). He stated during the interview that with a lack of ability to pick and choose jobs he must be more careful with money and make long range plans. He also said that he had invested in the gold market which was against his

lawyer's advice and done well. On the LSQ, Mr. B responded that he was very satisfied with his financial situation.

In summary as a result of the functional loss of his right hand and his impaired bowel and bladder function Mr. B had no intention of returning to the work force. Though he was forced to spend his life savings after his injury he is now financially secure as a result of an out of court cash settlement from his previous employer.

He now supports himself and his family very well on the earnings of his investments and his farm property.

As Social Companion

Social interactional history. Mr. B was a world traveller and stated he always looked forward to living. He stated that "the things I like the most are gone, travel, work" and that with his injury he had "lost 75% of what is important" (Item 170).

He enjoyed going out with work friends. Living in company compounds overseas made socializing easy. He worked hard and played hard. Mr. B described his social life before injury as "more active than now, now nil" (Item 139).

Upon being discharged from hospital Mr. B went home. At that time Mr. and Mrs. B had two children - ages seven years and one year. He spent most of his time "up" and would walk to the park. He also went every morning for physical and occupational therapy. During the first six months to a year post disability, he considered his social life to be "nil." Only his wife's family and the occasional old friend who would be "passing through" would visit (Item 140).

He said that they rarely went out and this was directly related to his bowel and bladder dysfunction. He used to enjoy the races and they went out to them once. Mr. B had an "accident" and never went again (Item 141). He states he doesn't go out more often because he is afraid of having an "accident" and he can't sit for long periods. Mr. B described his social life now as "isolated" and is "reluctant to go almost anywhere", so stays at home. He seldom drinks, though he used to, because of the interaction of the alcohol and his medication. There is "no one" he considers close to him, he is "alone with no contact" (Items 142, 143, 144, 145, 146).

At the time of the interview, Mr. B was living in the country, in his trailer on the site of his new home. This is a remote place with the nearest house approximately a quarter of a mile away and the town of Onoway over 10 miles away. He usually comes to Edmonton just for supplies and Mrs. B and the children come out every weekend.

Mr. B stated that the individual they now saw the most was Mrs. B's sister and that on occasion his neighbour would come by to say hello. The neighbour doesn't come by anymore and Mr. B stated "I don't make the best efforts myself - I could do a little more." He stated if he had bowel and bladder control it would make a big difference in his life style (Item 150).

When Mr. B responded to the LSQ (October, 1979) he was living in the city. At that time he said people came to see him approximately one to three times per month and that he got away from home for social and entertainment purposes the same frequency. He was not a member of any

organization, church, hobby or service, but since then has joined the Canadian Paraplegic Association (Item 152).

When asked if he would make any changes in his living situation, he said it was "OK now, with him in the country." Mr. B stated that there was now more work for his wife and things had changed. When she came to the site on the weekends she helped with the building, especially lifting. Their interactions were more "aloof, unaccessible, remote and uncommunicative." The focus of the marriage was now the children. Previously they were "very much in tune with each other sharing duties and spending time together." He said if it weren't for the children he would "tell her to go for her sake. She would have a better life."

When asked what things about life gave him the most pleasure, Mr. B stated "relationships with family or friends - watching the kids and when I do something I didn't think I could" (Item 173).

In response to LSQ on how many hours per week are spent in the nine listed activities, Mr. B said he spends 20 hours watching TV or listening to the radio and 10 hours reading. Now on average days he will spend three to four hours working on the house and checking the fences. He takes walks with the dog and spends the rest of the time in the trailer. He is able to sit four to seven hours at a time but this varies day to day.

In summary, Mr. B has withdrawn from social interactions because he does not want to have an "accident" in public. His wife is his primary companion and this interaction presently takes place only on weekends. He has made no effort to meet or socialize with neighbours and has gone from being a social, active "man of the word" to a recluse in the

country. He spends his time on self care and on finishing the large home he is building on his quarter section.

As Sexual Partner

Sexual function. In the fall of 1979 Mr. B responded to the LSQ and stated that with his sex life, he was "very dissatisfied." At the time of the interview Mr. B was still dissatisfied with his sex life. He said he lacked interest and that SCI related physical problems (bowel and bladder problems) were the two main reasons (Item 163). He stated that there had been a reduced frequency of intercourse since his injury. He is able to have a partial erection but has no sensation and can sustain it only for a short period (Item 162). He stated that he used to be very active sexually and that his marital sex life pre-injury was very good. Prior to his marriage he had travelled the world and said that he had had many girls. He also told the interviewer that "you'd better not ask her [wife] about sex because she won't tell you." He stated that it wasn't good anymore. Now they might touch each other and attempt to have intercourse perhaps once a month. Before his injury Mr. B said it was not uncommon to have intercourse twice a night (Item 161).

Mr. B did not have any sexual counselling; as previously stated he refused to have counselling of any type (Items 165, 166). Since his injury Mr. and Mrs. B have had a baby. The baby is approximately a year old.

He spoke openly during the interview; his voice became quite forceful at times and then it would change reflecting his sadness. He was very dissatisfied with his sex life and his inability to perform as he had

prior to his injury. Mrs. B did have a baby last year but from Mr. B's account, his loss of sensation and his bowel and bladder dysfunction had a significant effect on his desire to have intercourse.

Mrs. B.

Interview situation. Mrs. B was of small stature, muscular but not heavy with obvious marks of a surgical repair to her upper lip (possible cleft palate). Eye contact was limited and her posture throughout the interview was immobile. Voice tone was strong but response content was limited and she offered little spontaneous information.

When first asked if she would agree to be interviewed she said that the interviewer would have to ask her husband. She was co-operative but did not volunteer assistance.

Throughout the interview she was guarded both in posture and speech; constantly saying that there was "no change" or "I guess everyone has...." Only on two occasions did she spontaneously reply or add content. Once in regard to the children and the other time was during her description of her husband's expectations of her behaviour.

Mrs. B's. account of the active treatment period. Mrs. B lived on the mainland in a company compound with the two children. On the day of Mr. B's accident she said she received a phone call from the manager informing her of the fall and there was the possibility of internal injuries and that Mr. B had pain in his legs. Later another phone call said Mr. B had a compound fracture of his right arm, a broken pelvis and he was paralysed from the waist down. Mrs. B went by Landrover and then by boat to the hospital. When she finally arrived at the hospital

there were not any professional staff on duty and he was heavily sedated. Mrs. B was very "upset at the sight of him."

In order to visit Mr. B, Mrs. B had to travel 30 miles on rough roads by company Landrover, take two ferries and cross a border. This she did carrying one baby having left the other child at home with a neighbour.

The information that she kept getting at first was that he had fractures and he would eventually get better. Eventually she was told that "something was pressing on the bladder" and "they didn't have the facilities to operate." It would be better if he went to Edmonton and "it would be OK." Mrs. B received three days notice of the intended transfer. It was impossible for her to be ready and she and the children remained behind for approximately seven to ten days. She sold things at a loss, crated their personal possessions which the company agreed to air freight. She said her neighbours were very supportive assisting her to liquidate items and looking after the children. When Mrs. B finally arrived in Edmonton she stayed with her sister.

When asked what she was told about the meaning of her husband's injury she stated that the staff was evasive, "He wouldn't be the same, I suppose it must have been explained. [Mr. B] said it would get better." The doctor sat down with Mrs. B after a visit from an unnamed health professional (later determined to be a social worker). "[Doctor] sat down after that idiot man spoke to me who said [husband] wouldn't be able to perform sexually any more and laughed. I got up and walked out."

Mrs. B said she took one day at a time and did not think about the future. When asked if anyone else discussed the implication of Mr. B's injury and her feelings she said no; she didn't even discuss it with her

sister "There are somethings you don't share." Mrs. B stated she hoped things would get better but didn't really believe that there would be a change. "I didn't want to dump on him." When asked what her feelings were at that time, she said "I must have felt depressed - anybody would."

Mrs. B felt that the hospital care was good and she was satisfied with the treatment Mr. B received. He was able to come home on weekends and that helped. Mrs. B couldn't drive and had the children to care for.

In summary, it was difficult for Mrs. B to be with her husband during the early stages of his injury because the hospital was not easily accessible by normal travel. She was not told the seriousness of her husband's injury till she reached Edmonton, almost a month after the accident. Though the hospital care was good, Mrs. B did not find some of her interactions with the professional staff to be helpful. She attempted to support her husband's view that he would improve but didn't really believe that there would be much functional improvement. It was a very stressful time for her yet she didn't share her feelings with anyone.

Occupational and financial concerns. Mrs. B never believed that her husband would return to work, though Mr. B felt he would be able to return. When asked if she ever discussed this with him she said "I didn't want to bother him; I did a lot [of thinking] on my own." Mrs. B responded to, "what one thing prevents Mr. B from returning to work," that it was his lack of bowel and bladder control. "I think it has a psychological effect on him. I heard him say if that wasn't a problem, he might go back to work."

When Mr. B had used all his savings to support the family Mrs. B attempted to look for a job. Her work experience was very limited as was

her education. Mrs. B was born in Northern Alberta and lived, till the age of twelve, in a remote area where her father ran a trapline. Her schooling was through correspondence, supplemented by her mother's teaching. Later they moved to Fort McMurray where she continued in school till grade nine. She then found a job in a coffee shop where she met Mr. B. She was sixteen at the time.

Mrs. B was unable to find employment close to the house or with hours that would fit her home schedule. It was necessary for them to go on welfare. She managed by being frugal and "looking for bargains." This was for the eight month period before Mr. B received a disability settlement. From that time on there weren't any financial concerns. Mr. B handled the money management and Mrs. B did the household chores and cared for the children. When asked if things changed with them as a result of the injury, Mrs. B responded that they were "a little different." She said she had become more independent and had more things to do. "It really doesn't bother me on the whole, only certain things."

In summary, Mrs. B never felt her husband would return to work. When their life savings had been spent in supporting the family, she attempted to find a job but was unsuccessful. During this time they lived on welfare and Mrs. B shopped for bargains. When a settlement was received from Mr. B's previous employer it solved their financial concerns but did not change Mrs. B's workload.

Marital Relationship Before Injury and Post Injury Changes in Psychosocial and Sexual Activity

Psychosocial activity. Mrs. B described her husband prior to injury as a hard worker, outgoing, easy to get along with, as having a sense of humour and being affectionate in private. While they were overseas they went to parties, barbeques, shows and downtown to the "open cafe." There was a close social network of English speaking people and they would often meet and would go out in groups.

When Mr. B was off shore, Mrs. B used to go out with a girl friend to a show. She only did this occasionally because Mr. B was suspicious of her activities. When asked to rate her marriage before the injury Mrs. B said she didn't know but they "usually were together all the time."

Following his injury, Mrs. B described her husband as less happy, less sociable and harder to get along with. When asked if she thought Mr. B felt different about things between them, she answered he felt different about himself. She was encouraged to expand her statement and said that some days he "was depressed about the injury saying he couldn't do anything." She qualified this by saying "only on certain days, but again I would probably do the same."

Mrs. B said that since the injury she stayed at home more and she wasn't free to come and go. "When he is around he expects me to stay around too. I only go shopping and take the baby." Since Mrs. B spends most of the week alone in town, the interviewer asked her if she went out occasionally with a friend just for some adult companionship. Her response was one of the few animated ones she gave. "He would be upset and think I was looking for someone else. Once when he was in hospital I

went to the horse races with my sister. You'd think I'd committed a crime! Now it would be ten times worse!" When asked what she did for her own enjoyment she bit her lip and said "Nothing. I go shopping with the baby." When asked if she ever considered leaving she said "Never, I haven't yet."

Their social life has changed which is more a result of having few friends in Edmonton than of Mr. B's disability. Most of their friends are on foreign service and drop in only when they are going through Edmonton, making a special trip to see Mr. B. Now with Mr. B living in the country, Mr. and Mrs. B do even fewer activities together.

Mrs. B could not think of anything about Mr. B's adjustment which concerned her. On rating Mr. B's adjustment to his spinal cord injury she said "One or two, I can't put it on a scale because I don't think he really has."

When asked if she was lonely, Mrs. B said "not really - I keep too busy." In response to "Are there things which you enjoyed doing but have given up?" Mrs. B said "Yes, time to myself." In attempting to rate her overall adjustment to her husband's injury, she said "I can't put in on a scale. Nobody would like it - but a person gets used to it. I should after all these years."

In summary Mrs. B described her husband as being depressed and having never adjusted to his injury. They don't have any social life and this is now compounded with Mr. B living in the country and Mrs. B living in the city. All her activities are family centered and even her outings include taking the baby along.

Sexual activity. Mrs. B avoided any discussion of sexual activity. She did state that her husband was "affectionate in private" but didn't volunteer any other information when prompted. She left one specific question on sexual activity blank on the Dyadic Adjustment Scale. This was in keeping with Mr. B's warning that she would not discuss the area. Mrs. B had had one successful full term pregnancy since Mr. B's injury.

When asked if she had any especially negative unhelpful experience after Mr. B's accident she said "Yes, that idiot social worker!"

In summary Mrs. B would not discuss sexual activity when it was indirectly approached and she offered no openings for an exploratory discussion.

Dyadic Adjustment

Marital dyad pre-injury.⁴ Mr. B's total Dyadic Adjustment score was 124 out of a possible 151 for his marriage prior to injury. Mrs. B's total Dyadic Adjustment score for the same period was 102. Only the dyadic cohesion subscale had agreement. The greatest discrepancy was in the affectional expression subscale with a 42 percentage point scale spread, followed by dyadic satisfaction with a 16 percentage point scale spread, and then dyadic consensus with a 13 percentage point discrepancy. Table IV summarizes the pre-injury raw scores Mr. & Mrs. B attained on the Dyadic Adjustment Scale and its subscales.

⁴ See Table I for scale variables and subscale notations.

TABLE IV

Married Respondents' Dyadic Adjustment Scale and
Subscale Means as Compared to Pre-Injury Scores
for Dyad B

Scale	Spanier's Married Respondents' Mean Scores	Highest Possible Score	Mr. B	Mrs. B
Affectional Expression	9.0	12	12	7
Dyadic Consensus Subscale	57.9	65	58	49
Dyadic Cohesion Subscale	13.4	24	11	11
Dyadic Satisfaction Subscale	40.5	50	43	35
DYADIC ADJUSTMENT	114.8	151	124	102
	N=218			

When asked to rate their marriage before Mr. B's injury, both stated that it was extremely happy and almost always agreed on major decision making, finances, aims and goals and household tasks. They had total agreement on career decisions. As a heavy duty mechanic supervisor on offshore oil rigs Mr. B was doing very well making in excess of \$20,000.00 per annum without benefits. Their standard of living was high.

Socially they were quite active when Mr. B was on shore. There are differences in their perception of agreement in this area. Mr. B had a 1 scale point higher amount of agreement in all areas considered - friends, leisure time, interests and activities, amount of quarreling and the frequency they got on each other's nerves. They agreed on the amount of time spent together and the amount of time spent on working together on projects, but there was a 3 point scale spread in the amount they confided in one another. Mrs. B perceived it to be most of the time while Mr. B said it happened rarely.

In response to agreement on sex relations and demonstration of affection, Mr. B stated they always agreed while Mrs. B said occasionally they disagreed, a 2 point scale spread. They both agreed that there was no problem in showing love. Mr. B said that there was never a problem with "being too tired for sex." In response to this question Mrs. B said "I'll leave this one out."

Neither of them ever regretted their marriage. Mrs. B said that she wanted desperately for the marriage to succeed and would go to almost any length to see that it does. For the same period Mr. B stated that he wanted very much for his marriage to succeed and would do his fair share to see that it did.

In summary prior to his injury Mr. B scored 124 on the Dyadic Adjustment Scale which is higher than the mean for married respondents, and Mrs. B scored 102 which was less than the mean scale score of 114.8 for married couples.

Marital dyad post-injury. Mr. B's post-injury Dyadic Adjustment Scale was 87 and Mrs. B scored 89. This was a 24% decrease in the Dyadic Adjustment score for Mr. B when compared with his score for his pre-injury relationship and a 9% decrease in the Dyadic Adjustment score for Mrs. B when compared with her score for the same period. Table V summarizes the scores Mr. & Mrs. B attained on the Dyadic Adjustment Scale and subscales.

For Mr. B the range of post-injury Dyadic Adjustment subscale scores was 2-51 representing 83% to 12% decrease in previously attained scores. Both Mr. & Mrs. B rated their marriage post-injury as less happy than before Mr. B's injury. Mr. B by 2 points and Mrs. B by 3 points.⁵ The greatest discrepancy in score change between Mr. & Mrs. B occurred on the affectional expression subscale. Mr. B's subscale score of 2 represented a 83% score decrease and Mrs. B's score of 5 represented a 16% score decrease resulting in a 25 percentage point spread. This represents a 17 percentage point decrease between Mr. B and Mrs. B's from their pre-injury scores.

The greatest decrease in subscale scores for Mr. and Mrs. B also occurred on the affectional expression subscale. As previously stated

⁵ See Appendix E for item scales.

TABLE V

Married Respondents' Dyadic Adjustment Scale and
Subscale Means as Compared to Post-Injury Scores
for Dyad B

Scale	Spanier's Married Respondents' Mean Scores	Highest Possible Score	Mr. B	Mrs. B
Affectional Expression	9.0	12	2	5
Dyadic Consensus Subscale	57.9	65	51	44
Dyadic Cohesion Subscale	13.4	24	7	11
Dyadic Satisfaction Subscale	40.5	50	27	29
DYADIC ADJUSTMENT	114.8	151	87	89
	N=218			

Mr. B had an 83% decrease and Mrs. B a 16% decrease. The dyadic satisfaction subscale had the next greatest decrease in score by both Mr. and Mrs. B. Mr. B had a 32% decrease and Mrs. B had a 12% decrease resulting in a 4 percentage point spread between their subscale scores.

The two remaining subscales dyadic consensus and cohesion reversed position for Mr. and Mrs. B in regard to percentage decrease of subscale scores. Mr. B had a 17% decrease on the subscale score for dyadic cohesion and Mrs. B had no change. This resulted in a 17 percentage point difference. For dyadic consensus, Mr. B had a 10% decrease in score and Mrs. B had a 7% decrease, resulting in a 11 percentage point spread.

There was an increase in disagreement over consensus present in handling of finances, in major decision making and household tasks. In this area there was a 1 scale point drop for Mrs. B resulting in a 2 point spread. In the area of household tasks, there was a 2 point increase in disagreement when previously there was complete consensus.

With social interaction, there was complete agreement on friends and frequency of quarrels but both areas had a decrease in scale points. When asked how often they go on each other's nerves, Mr. B went from rating it "rarely" to "more often than not" which was a 2 scale point decrease while Mrs. B remained the same at "occasionally." Similarly there was an increase in agreement over the number of times they confided in one another. Mrs. B's score remained constant at "rarely" while Mr. B said it was now occasionally as opposed to "most of the time" before his injury.

There was an increase in disagreement of 3 scale points for leisure time interest and activities, working together on projects and of 2 scale points for engaging in outside activities.

When asked how often they thought things were going well between them, Mr. B's response remained the same at "all of the time" and Mrs. B said it was now "occasionally" instead of "more often than not."

In rating sexual relations Mrs. B stated that there was occasional disagreement, while Mr. B said the relationship had deteriorated to almost always disagreeing. As previously stated the affectional expression subscale had the greatest score decrease for both Mr. and Mrs. B and also had the greatest percentage point discrepancy for all subscales. This included decreases in demonstration of affection and showing love. There was also a decrease in the frequency of kissing as rated by Mr. B but Mrs. B's response remained constant.

Both Mr. and Mrs. B described a decrease in their marriage happiness; Mrs. B now described it a little unhappy and Mr. B described it as happy while previously it was described by both of them as extremely happy: Mrs. B says she never regrets her marriage while Mr. B now says he regrets "all the time."

In summary there has been a marked decrease in Dyadic Adjustment scores assessing the quality of marriage for Mr. B and a lesser decrease in Mrs. B's score. There has been a change in the rating of marriage happiness for both, with Mr. B describing the greatest deterioration. Mrs. B stated it would be nice if her relationship succeeded but she couldn't do much more than she was doing now. Mr. B stated he wanted

very much for his relationship to succeed and will do all he can to see that it does. He then added "but its up to her."

SUMMARY

Two dyads have been reviewed presenting the history of the injury and the husband's response to the rehabilitation process. A description of previous and current role functions of the SCI as breadwinner, as social companion, and as sexual partner was presented as documented by hospital records and interviews of both the spinal cord injured husband and spouse. A measure of the quality of the marriage as indicated by scores on the Dyadic Adjustment Scale was also presented.

CHAPTER VI

RESEARCH QUESTIONS AND DISCUSSION

The research questions will now be addressed comparing the findings for Dyad A and Dyad B. Symbolic interaction is used as the conceptual framework to analyze and interpret the data.

The questions formulated for this exploratory study of the SCI husband and spouse were as follows:

1. How has the dyad adapted to the changes dictated by the husband sustaining a spinal cord injury?
2. What are the present role behaviours of the dyad for:
 - a) the breadwinner role?
 - b) the social companion role?
 - c) the sexual partner role?
3. What is the overall dyadic adjustment once the role behaviours have been stabilized?

Research Question 1

How has the dyad adapted to the changes dictated by the husband sustaining a spinal cord injury?

The intent of this question is to determine the process that the

marital dyad goes through from the moment of the traumatic incident, to the time of the emergence of new dyadic roles. Through the analysis of this process three stages emerged which will be presented as a structure for the interpretation and discussion of Question 1. As the writer was using the symbolic interaction concepts to explain the individual dyads' adjustment process, a continuum emerged. Upon further analysis, it was apparent that the continuum was common to both dyads. An attempt was then made to use only the concepts that contributed most significantly to a more generic description of the process. Once this was done, the concepts were grouped and the three stages were identified. These are: Assault, Upheaval and Recovery. The data from both dyads will be integrated within the presentation.

Stage I - Assault

Based on their overall appraisal both Dyad A and B stated they were extremely happy with their marriages prior to the husband's injury. Both dyads were functioning adequately within the marriage and in particular in the three roles under investigation: breadwinner, social companion and sexual partner. At the time of the accident these were accepted dynamic dyadic roles that were meeting the expectations of the actors. One would expect that following a traumatic injury which resulted in a major disruption of the marital dyad, that the respondents would rate their pre-injury marriage more highly.

The impact of the spinal cord injury was such that it stopped immediately the husband's ability to actively continue meeting the role expectations of his spouse. The roles of social companion and sexual

partner came to an abrupt halt and only the role of breadwinner continued, but in a modified manner. Mr. A and Mr. B were both covered by sick benefits and insurance plans so were able to provide support to their families for an extended period. There was a disruption in the husband's roles as a direct result of injury and a disruption in the wife's roles as an indirect result of her husband's inability to perform roles. Mrs. A and B were required to continue with the normal roles such as wife, homemaker and child care provider and accommodate the change in their routines dictated by making hospital visits and attending to their husband's needs. Both women said they had become more independent and assumed more responsibilities during the time their husbands were totally incapacitated. This was not a unique situation for either woman, as Mrs. A did have a form of employment, babysitting, which required some organization and role juggling. Though Mrs. B. was never employed during marriage she functioned as a single parent for extended periods of time when Mr. B was on an offshore job. Both women were capable and over the years had developed skills and resources on managing the demands of their living style.

Stage II - Upheaval

As a result of the role disruptions brought on by a permanently disabling accident, there were fluctuations in self concept of both Mr. A and Mr. B as reported in the hospital records and the interviews. Both men had periods of depression or despondency and exhibited various ego defences such as denial, withdrawal and aggression. These manifestations

of change in self concept were influenced by the interaction process first in the hospital and then in the home.

The self at this time is very fragile and attempting to re-integrate; all previously used defence mechanisms and behaviours seem ineffective. There is a loss of control over one's bodily functions and independence. Within the hospital there were numerous symbols such as wheelchairs, bedpans, unresponsive limbs which communicated indirectly a loss of independence and there were also the direct communications of staff "you won't walk again, won't be the same" all of which are indicators of a decrease in status - able-bodied to disabled, with its accompanying stigma.

The behavioural repertoire for the husband was gained through being an able-bodied person. Now his primary reference group had changed to patients on the ward with similar disabilities. Later his reference group would be other disabled individuals in the community.

For the spouse, the significant patterns and communications of marital interaction were developed with an able-bodied individual. Now, that her husband is SCI, these previously developed patterns seem no longer adequate. She too was distressed. There was a period of denial and disbelief. This was often fostered by the husband's denial of the seriousness of the injury and further supported by inadequate explanations from the hospital staff on the implications of her husband's "broken back." She had in most instances not had any experience with disability, and was faced with a situation that requires a new response.

There wasn't any time to prepare for the permanent changes occurring in her life and the alterations in her marital dyad roles. There had to be a redefinition of the situation.

From the interaction with staff, the reading of the environmental cues, the interaction with a husband with a fluctuating self-concept and permanent change in physical status a redefinition of the situation for the marital dyad was formed.

A new definition of the situation required alterations to the dyadic roles of breadwinner, social companion and sexual partner. This was accomplished through communication and the role-taking and role-making process on the part of both husband and wife. A description of the process to this point follows for each of the three roles.

Dyad A

Breadwinner. For Dyad A there was a lack of consensus over the definition of the situation for all three roles. Mr. A's definition was seriously influenced by his decrease in self concept as exhibited by his depressed affect. He lacked the impetus to initiate and to engage in new situations and new social interactions. Mrs. A's definition was influenced by her role expectations for her husband which were partially formed when he was able-bodied and partially formed through her experience with him as disabled.

Both describe the events similarly but assigned different values to the accuracy of their role-taking and role-making. Mrs. A realized that if the family were to maintain a similar life style Mr. A would not be able to provide it. As a result she began her own business. Mr. A recognized his wife's abilities and expected her to be successful.

First, he withdrew and then he relinquished the status of primary breadwinner. Instead of being able to combine their resources for mutual satisfaction through a formal modified role reversal, Mrs. A's response only served to create a greater division between them.

Mr. A's physical prowess and masculine image was very important to his self-concept and his perception of himself as breadwinner. Even though Mrs. A did earn extra money through child care activities this was congruent with Mr. A's perception of homemaker not breadwinner. He did not perceive Mrs. A's activities as contributing to the family's support. To Mrs. A, her business adventure was a challenge and an opportunity to show that she could make it in the work field. The real accomplishment was her ability to still fulfill her usual dyadic roles and take on a new role as breadwinner.

Social companions. As social partners Mr. and Mrs. A were at first able to perform satisfactorily. They attended functions connected with Mr. A's new reference group the disabled, but when Mrs. A invited old friends, their previous reference group, Mr. A became very unsociable and moody. Eventually people no longer came to call. It seems Mr. A's role-taking assumed that he would be rejected and in response he became the inhospitable, abusive host which was a radical change from his previous role. Mrs. A found role-taking difficult as she never knew what to expect from Mr. A. She stopped inviting people and became socially isolated. It was not till she attended a family wedding did he realize how much she too had withdrawn.

Her major form of socialization came through her work and association with her sister from 10:00 p.m. to the early hours. The demands of her

multi-roles and her physical exhaustion didn't permit time for herself, or to go out. She became very dissatisfied.

Sexual partners. As sexual partners, there was a decrease in meaningful communication. A spinal cord injury increases the need for use of verbal communication as some non-verbal communications such as touching, stroking, are no longer functional because of the absence of sensory pathways. New anatomical areas which will stimulate arousal must be found through a trial and error method validated by verbal feedback.

It seems that Mrs. A was more willing to engage in role-making than was Mr. A. The new definition of the situation may call for sexual role reversal and a willingness to experiment. With an altered self concept of the husband, there is lack of desire to initiate action and explore a new situation such as experimenting with sexual options such as cunnilingus.

Dyad B

Breadwinner. For Dyad B, although there was an alteration in employment status for Mr. B. he did not lose his overall status as breadwinner. The cash settlement he received was more than adequate to not only maintain but increase the dyad's standard of living. Another consideration was that Mrs. B. was not a threat to his role as she could not find employment.

Though Mr. B's physical disability does preclude his returning to his old job, he could have used his skills and experience in a related

capacity. This he was not willing to do because of his view of himself. Though he no longer meets his own expectations in the actual performance area of his previous occupation, he has not accepted "the disabled" as his new reference group. He doesn't wear his assistive walking devices or use a wheelchair for conservation of energy - both symbols of being handicapped.

Returning to work is further restricted by a lack of role-taking accuracy. Rather than risk rejection or embarrassment because of his perceived lack of status and bowel and bladder disorder, he has chosen not to put himself in the position of having to respond.

Social companions. As social companions, Mr. B's definition of the situation takes precedence. He perceives himself as deviant with his lack of bowel and bladder control and therefore will not engage in social activities. Mrs. B. has imposed social isolation on herself as she anticipates an explosive response from Mr. B. if she were to go out alone. She remains at home, consciously denying herself the company of her previous reference group and family.

Sexual partners. Since we are lacking some documentation of Mrs. B's sexual role behaviour it is only possible to comment on Mr. B's adaptive responses. Sexual prowess was very important and contributed to his self image as a man of the world. Lack of sensory feedback and an alteration in self concept both contribute to his lack of sexual satisfaction. There is vaginal penile intercourse as Mrs. B. had a baby during the year. This could have been a direct attempt on Mrs. B's part to raise her husband's self esteem by unequivocally validating his potency, or it

may have been an accident through ignorance. They never accepted any sexual counselling.

Stage III - Recovery

Role alterations within the dyad overtime become established and from this emerges new dyadic roles. These new roles are then accepted or rejected by the husband and wife. This results in either a continuation of the dyad's new stabilized roles or a dissolution of the dyad.

The adjustment process for the marital dyad following the husbands' traumatic spinal cord injury can be conceptualized as moving through three stages. The term Assault begins in Stage I, with Stage II depicted by Upheaval, and finally the Recovery completes the process for Stage III. These stages may be schematically viewed in Figure 1, Three Stage Adjustment Process of SCI Marital Dyad.

In retrospect, the three stage adjustment process appears to be similar to crisis models in family literature. The salient difference is that the crisis model does not have a specific temporal reference beyond the precipitating event. With the Three Stage Adjustment Process, adjustment or problem solving begins during the hospitalization period, but is only developed following discharge. This can be at least eight months after the traumatic event. Another important difference is that the help of skilled professionals is required at various times throughout the adjustment process. The dyads' personal resources are insufficient to resolve their difficulties.

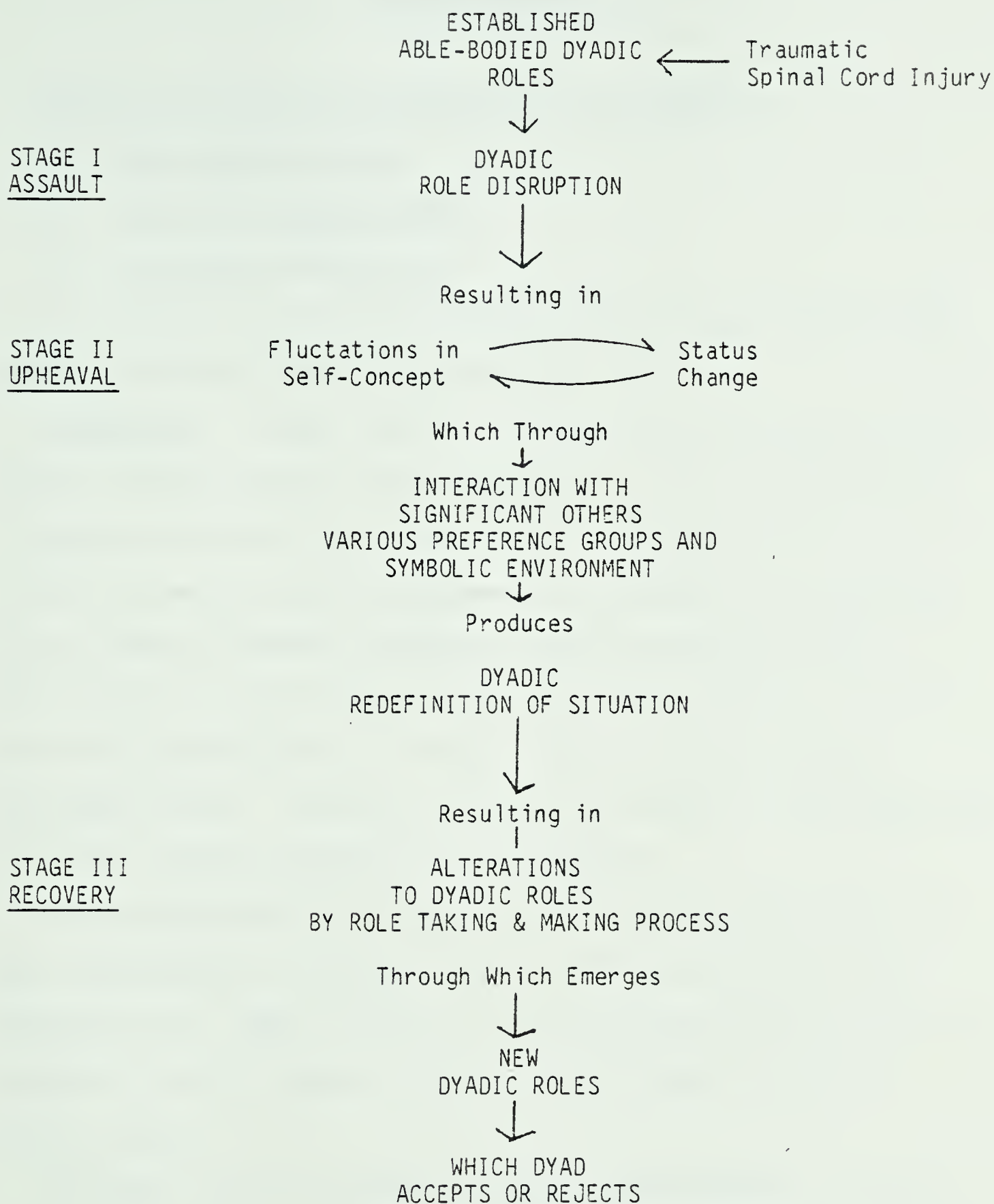


Figure 1

Three Stage Adjustment Process of SCI Marital Dyad

Research Question II

What are the present role behaviours of the dyad for:

- a) the breadwinner role?
- b) the social companion role?
- c) the sexual partner role?

For Question II data relevant to both dyads will be presented under each of the specific roles being discussed.

Breadwinner. In Dyad A both Mr. and Mrs. A are fulfilling this role but Mrs. A has become the primary breadwinner. This role reversal was dictated by the definition of the situation - inability of Mr. A to return to an equal status of employment which resulted in a significant loss of income. From the literature it would be expected that Mr. A. would return to a work situation. He had partially completed grade 12 and taken advanced technical training. He had a stable pre-injury employment history. He was able to drive and he was of an age group that had a more objective assessment of its potential.

It has been noted that in families with the wife employed there is more disharmony and a shifting of power to the wife (Collette, 1969; Wittkower et al., 1954). Certainly this was the case with Dyad A, Mr. A. resented his wife's success in business and the power she gained in decision making.

For Dyad B there is no change in the role behaviours Mr. B is the breadwinner and Mrs. B is responsible for household management. As with Dyad A there is financial security, but the means by which it was attained is different. Mr. B is not employed, but generates revenue for

his investments and his farm. This is more than sufficient to allow him to maintain his breadwinner status. He has all the same employment potential characteristics as Mr. B but has a more serious physical dysfunction - lack of control of bowel and bladder. This has been cited as important enough to preclude re-employment (Dunn, 1977).

Social companion. This is a dyadic dysfunctional role for Mr. and Mrs. A. Mr. A has rejected all old friends except one childhood buddy and has withdrawn. His behaviour was abusive toward Mrs. A and he seemed to use her as a display to maintain his social status rather than to interact with her at social gatherings.

Mr. A's social matrix post-injury had dwindled, but Mrs. A was unable to supplement her companion role because of her work situation. Mr. A turned to more sedentary activities such as watching T.V., listening to the radio and reading (Christopherson, 1968; Rogers & Figone, 1979; and Ludwig & Arndt, 1980).

As noted in the history Mr. A was a motor-oriented, active outgoing individual. His quadriplegia will restrict some of these activities though his premorbid personality and behaviour would predict eventual re-establishment of the social companion role (Mueller, 1962; Litman, 1964). It would seem that now that he is separated that he is going through role socialization and he will eventually be more socially active. The delay in re-establishing this role which was associated with his lowered self-concept, was a contributor to his marriage dissolution. Mrs. A is currently re-establishing her social contacts and becoming more active.

In contrast to Mr. A, Mr. B had withdrawn totally from social interaction. His previous social interaction pattern was related to his work history; outings, and drinking with work companions. Also his work has been overseas for three and a half years which has prevented establishing a social network in Edmonton. Since he is no longer working and has not established a new reference group, opportunities for social interaction have diminished. This was now further complicated by his move to the country. He therefore has the premorbid characteristics for role re-establishment but has denied himself the socialization process. This is partly due to circumstances beyond his control but is also self imposed, because of risk of an "accident" and personal embarrassment. New et al., (1968) and Dunn (1977) stated that lack of bowel and bladder control would restrict social interaction.

Mrs. B is willing to accept these conditions rather than risk Mr. B's wrath. As cited previously, individuals with poor tension management techniques are less likely to relate well on an intimate basis (Carlson, 1979). Mr. B. has always been in control of the dyad and his life. He now finds it very frustrating to accept assistance and now is more difficult to get along with. Mr. B's age is also a factor, as cited earlier older patients experienced more social discomfort following a SCI (Dunn, 1977). When this is coupled with his bowel and bladder dysfunction it can produce significant deterrents to engaging in social situations.

Though this is not a satisfactory role function for the dyad there seems to be no attempt on Mrs. B's part to alter it. It would seem that this role is not essential to the continued endurance of Dyad B.

Sexual partner. Again this is a dysfunctional role for Dyad A. The lack of satisfaction with roles was identified by Mr. A as the major contributing factor to the marriage break up. Mr. A stated he wished to find someone who will accept him as he is. Mrs. A stated she attempted to alter her behaviour to fit the situation but met with resistance. It appears that Mr. A is attempting to establish a new reference group, a significant other, who would know him as disabled. With this, there will be no need to be faced with sexual role expectations fashioned when he was able-bodied. Mr. A's unwillingness to experiment with sexual acts was an effective way of increasing the distance between himself and his wife (Knoor & Bull, 1970). Both Mr. and Mrs. A are sexually inactive at this time.

Mr. B states that he is highly dissatisfied with his sex life but we are aware that some form of penile vaginal intercourse can take place and does. Part of his dissatisfaction is related to his bowel and bladder dysfunction for which Mrs. B has to assume an orderly role. Her dissatisfaction with performing orderly functions detracts from the definitions of a sexual situation. This influences his view of the situation and alters his behaviour. There is no evidence of sexual experimentation and no form of counselling ever took place. In fact it was rejected. Though Mr. and Mrs. B. are sexually active it does not seem to be mutually satisfactory. This confirms the review of the literature presented earlier (Sadoughi et al., 1971; Fitzpatrick, 1974; and David et al., 1977).

Research Question III

What is the overall dyadic adjustment once role behaviours have stabilized?

An overall measure of dyadic adjustment was done using the Dyadic Adjustment Scale (Spanier, 1976). A discussion of the dyads' perception of the four sub-scales also follows. They are: affectional expression, dyadic consensus, cohesion and satisfaction. In order to compare the findings all scores have been converted into a percentage of the highest score available for the Dyadic Adjustment Scale and the four sub-scales. The dyads will be integrated for presentation purposes.

Overall adjustment. The dyadic adjustment scores for Dyad A and B have radically decreased for the period post injury when compared to the period prior to injury. This indicates that the changes that have occurred within the dyad as a result of the husband's spinal cord injury have not enhanced the marital relationship but have severely detracted from it. The spinal cord injury of the husband produced such radical changes in roles for Dyad A that they could not agree sufficiently on new roles and ultimately rejected the dyad. For Dyad B the changes were equally severe, but they were able to tolerate the alteration in the various roles sufficiently to accept new dyadic roles.

When comparing the dyad's appraisal of their marriage, Dyad A went from appraising their marriage above the mean score for married respondents (75%) at 81% and 77% respectively for Mr. A and Mrs. A to 48% and a devastating 22%. Dyad B went from pre-injury scores of 82% and 68% to 58% and 59% respectively for Mr. B. and Mrs. B.

Dyad A and Mr. B had above the norm ratings of their marriages, but Mrs. B's score of 68% was below the norm for married couples but above the norm for divorced respondents (46.8%).

It is quite possible because of their current disabled state that both Mr. A and Mr. B perceived their marriages better than they actually were. For Dyad A the eventual dissolution of their marriage could also serve as a stark contrast to their previously functioning relationship. This could influence their ratings. Mrs. A's score is congruent with the mean score for the married sample (Spanier, 1976).

For Mr. B, his physical dysfunction is so devastating that he can see very little that is positive about his current life. In contrast all that went before had to be better. Mrs. B was the only one who did not idealize her marriage prior to her husband's injury. She seemed to be aware of areas that were less than to her satisfaction but she was willing to accept them, as indicated by the Dyadic Adjustment score.

Subscale Rank Order

To more closely analyze the dyad's perception of their relationships, each subscale score was expressed as percentage of the highest score attainable for that subscale and then the four subscales were rank-ordered. The highest percentage attained was placed first and so on. The differences between each respondent's particular score for a subscale was also rated.

In Dyad A, for the pre-injury period, there was congruence over the rank order of the various subscale though there were differences in the individual scores attained. For the post-injury period, there was a re-ordering of the subscales but again the dyad was congruent in the new

rank order. There was also a substantial increase in individual score differences. The data are presented in Table VI.

For Dyad B, there was a lack of congruence over the rank order of three of the four subscales for the pre-injury period as, as well as substantial differences in individual scores. For the post-injury period there was congruence over the rank order of all four subscales and for three subscales a decrease in individual score differences. The data are presented in Table VII.

Dyad A has perceptual congruence of the various functioning units of their marriage even though they differ in their individual qualitative appraisals. For example they both rated the affectional expression subscale the highest, but there was an 8 percentage point difference in their individual scores. They appear to be able to generally define the situation congruently but lack the ability for accurate role-taking. As a result the action taken was often futile or produced another chain of events which caused more disharmony. It would seem from this dyad that congruent perceptions have little effect on problem solving a troubled dyad. It may have in fact facilitated the dissolution. Both actors saw the situation to be so unworkable that the only course of action appropriate was the dissolution of the dyad. Table VI shows the percentage point differences on each scale for Mr. A and Mrs. A for the pre and post-injury period.

As previously stated Dyad B pre-injury, had a lack of perceptual congruence over the dyad's functioning units as represented by the various dyadic subscales. At this time there was also great individual

TABLE VI

Rank Order of Subscales and Score Differences by
Mr. and Mrs. A for Pre and Post Injury Periods

MR. A	Difference	MRS. A
<u>RANK ORDER BEFORE</u>		
+Affectional Expression	8	Affectional Expression
+Dyadic Satisfaction	6	Dyadic Satisfaction
Dyadic Consensus	6	+Dyadic Consensus
+Dyadic Cohesion	9	Dyadic Cohension
<u>RANK ORDER AFTER</u>		
+Dyadic Consensus	23	Dyadic Consensus
+Dyadic Cohesion	25	Dyadic Cohesion
+Dyadic Satisfaction	14	Dyadic Satisfaction
+Affectional Expression	17	Affectional Expression

+ Denotes higher score.

TABLE VII

Rank Order of Subscales and Score Differences by
Mr. and Mrs. B for Pre and Post Injury Periods

MR. B	Difference	MRS. B
<u>RANK ORDER BEFORE</u>		
+Affectional Expression	42	Affectional Expression
+Dyadic Satisfaction	16	Dyadic Satisfaction
Dyadic Consensus	14	+Dyadic Consensus
Dyadic Cohesion	-	Dyadic Cohension
<u>RANK ORDER AFTER</u>		
+Dyadic Consensus	11	Dyadic Consensus
+Dyadic Cohesion	17	Dyadic Cohesion
+Dyadic Satisfaction	4	Dyadic Satisfaction
+Affectional Expression	25	Affectional Expression

+ Denotes higher score.

differences in subscale scores. It was Mr. B whose scores were quite elevated when compared to the mean scores for married respondents. As a result it was he who had the greatest change in perception of the dyad's functioning post-injury. Mrs. B's score did not alter greatly. It would appear that the traumatic event of the spinal cord injury and its disruption of her husband's role behaviour did not make that much difference to her overall perception of the quality of her marriage. To her even though there were alterations in the dyad's role functions the situation was acceptable.

Why has this dyad remained together? Mr. B's injury has made his perception of the marriage more congruent with Mrs. B's perception. This may provide for more communication in that Mrs. B must now do more assisting with activities because of her husband's decrease in independence. He sees himself as less worthy but has a strong sense of responsibility for the dyad and the family. She does not think that her situation has changed so much to even consider leaving, therefore the situation is acceptable for the time being. It could be expected that her expectations are lower than her husband's as reflected by a linen dishcloth which hangs in her kitchen with the following phrase:

"Marriage is not expecting too much from one another".

Conclusion

The two dyads included in this case study have had major disruptions to the marital roles of breadwinner, social companion and sexual partner. From the initial stage of assault of the traumatic injury through the upheaval stage, these roles have been subjected to a dynamic

interactional process. It is through this interaction that new behaviours for the roles have emerged which were then evaluated by each dyad respectively. Dyad A rejected the new role behaviours which culminated with the dyads dissolution while Dyad B accepted the new behaviour and the dyad endured.

CHAPTER VII

IMPLICATIONS

The implications of this research will be presented with specific references to the research of the SCI marital dyad and consideration for the health care professional.

Dyadic Implications

In learning more about the process that a dyad goes through from the assault to the recovery stage following a SCI, it was apparent that the complexity of interaction requires data collection from a variety of sources. In particular it is critical to have the spouse's appraisal of the situation. Process studies, which focus upon alteration to the self-concept and to the husband's personality require the perception of someone else who has been part of the interaction. It is not just the individual that is affected but his social network as well. In particular his spouse is involved.

With dyads, more attention must be paid to both actors not just the individual. The traumatic event affects them both and the recovery process must be dealt with as it affects them as individuals and as it affects them as a unit. The symbolic interaction view of a relationship being a unity of interacting personalities is fundamental to this type of research.

To have an external view of the dyad's dynamics, it is also necessary to have reviewed factual information in the form of professional records when available. In some instances both the husband and the spouse hold a distorted perception of the events. It is through the cross referencing of data that a more realistic picture emerges. The case study method has met the objective of this study by allowing the researcher to explore the changes that occur within the marital dyad following the spinal cord injury of the husband and to identify an adjustment process.

In viewing the process it must be recognized that there is a period when the individual and the spouse selectively disregard the symbolic environment. This is a defensive maneuver to protect them from their worst fear that the injury will be permanently disabling and will alter their role behaviours. During this time it is this distortion in perception that often results in inappropriate behavioural responses on the part of the dyad. It is therefore necessary that this adaptive maneuver be recognized as just that - a protective mechanism and a critical stage of the process.

Research of this type has many ethical considerations. It involves delving into very personal areas and requires experienced interviewers who are able to probe but not offend. Though there is a danger of biased solicitations and response compliance, the personal interview does allow for exploration and clarification of information that would not be available through a questionnaire. The reading of the respondents' behaviour is just as important as the recording of their verbal responses, but also demands a responsible recorder. This type of research also requires careful consideration on the part of the

interviewer of the respondents' rights and privacy. The very personal nature of the approach could violate the parameters of the scientific method and be an invasion of privacy.

Consideration for Health Professional

The following considerations are put forth for health care professionals in the field in order to assist them to improve the quality of services currently offered.

1. It is imperative to be able to recognize the various stages of adjustment through which the dyad is going, to choose the time for appropriate intervention.
2. Specifically during the upheaval stage, the dyad is not ready to learn all the implications of the injury. Factual information is not processed especially if it is at all threatening.
3. Facilities should offer a variety of didactic and support experiences. Voluntary attendance at lectures and support groups which are offered on a regular basis should be encouraged. These groups should be made up of professional staff, patients, expatients and families. This will allow for sharing of experiences by those who have been there - at times a more credible source than the health care professional.
4. Meaningful record keeping is essential. The use of professional jargon has often been criticized but it is imperative that official health records use appropriate terminology that has accepted definitions and therefore has consensus for professional communication. Phrases such as "appears to be

cheerful" are interpretations not facts and add little to the individual's actual mental status, or stage of adjustment.

Behavioral description should accompany less definite terminology.

5. Finally large rehabilitation units should have a formalized schedule for comprehensive psychosocial workups of patients and where appropriate their significant others. Incomplete psychosocial documentation throughout the rehabilitation process makes any type of research in the field a very difficult task.

Recommendations for Research

It is recommended that research be undertaken to validate the stage adjustment process identified. It should have:

1. a larger sample;
2. adjustment measures which could be used in identifying dyadic problems and therefore serve as a predictor of deteriorations in the dyad.

Exploration of the stage adjustment process would be of assistance in further clarifying concepts of symbolic interaction and in adding to the body of knowledge of rehabilitation. For example much greater attention could be paid to the amount of role-taking and role-making that goes on within the SCI dyad as compared to able-bodied marital dyads. Once this is learned, it could be used to facilitate the SCI dyads' adjustment process and assist in intervention strategies.

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APPENDIX A
SURVEY LETTERS

the university of alberta

edmonton, alberta, canada T6G 2G4

telephone (403) 432-5990

department of occupational therapy
faculty of rehabilitation medicine

The Division of Rehabilitation Medicine at the University of Alberta Hospital, in conjunction with the Department of Occupational Therapy, Faculty of Rehabilitation Medicine, is conducting a follow-up study of individuals discharged from the Hospital's Rehabilitation Unit during the last five years.

Within the next two weeks a questionnaire will be mailed to you which will assist us in updating our information on previous patients and their current activities. Though your participation is strictly voluntary, it is hoped that you will take the time to respond. Your co-operation is necessary so that we can have accurate information to assist us in reviewing our present rehabilitation services and in planning future offerings.

As part of the review, as well as being sent a questionnaire, some individuals will also be interviewed. The interviews will be arranged at a convenient time and place.

You are asked to fill out the accompanying information sheet and return it in the enclosed envelope as soon as possible. Some difficulty is anticipated in reaching all those discharged from hospital between June 1973 and June 1978, because of changes in address. If you are in contact with anyone who was discharged from the Rehabilitation Unit during that time I would appreciate you giving me their name and present address.

As the consumer's view is a very important part of any service area, I hope that you will assist us.

Yours truly,

Sharon Brintnell, OTReg(C)
Associate Professor

SB/db
encl.

the university
of alberta



edmonton, alberta, canada T6G 2G4

telephone (403) 432-5990

department of occupational therapy
faculty of rehabilitation medicine

REHABILITATION UNIT FOLLOW-UP STUDY

INFORMATION SHEET

NAME _____

CORRECT
ADDRESS _____

_____ POST CODE _____

PHONE _____ AGE _____

MARITAL
STATUS ☐ single ☐ married ☐ separated ☐ divorced
 ☐ widowed

FOLLOWING PRIMARY INJURY, APPROXIMATE DATE
OF DISCHARGE FROM U.A. HOSPITAL _____

NAMES & ADDRESSES OF OTHER INDIVIDUALS

(1) NAME _____

ADDRESS _____

(2) NAME _____

ADDRESS _____

University of Alberta Hospital

112 St. & 83 Ave., Edmonton, Alberta, T6G 2B7 (403) 432-8822

the university
of alberta

department of occupational therapy
faculty of rehabilitation medicine

edmonton, alberta, canada T6G 2G4
telephone (403) 432-5990



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October 5, 1979

REHABILITATION UNIT FOLLOW-UP STUDY

Please find enclosed the copy of the follow-up questionnaire for individuals charged from the University of Alberta Hospital's Rehabilitation Unit as referred to in my letter of August 29, 1979.

As previously stated your participation is strictly voluntary, but it is expected that you will take the time to respond. Your co-operation is necessary that we can have accurate information to assist us in reviewing our present rehabilitation services and in planning future offerings.

A self-addressed, stamped envelope is included for your convenience.

An early reply would be appreciated so that I may begin scheduling, before 1st of November, appointments for those individuals who will be interviewed.

As the consumer's view is a very important part of any service area, I hope that you will assist us.

Yours sincerely,

E.S. Brintnell
Associate Professor
Department of Occupational Therapy
University of Alberta

kk
enclosure

University of Alberta Hospital

112 St. & 83 Ave., Edmonton, Alberta, T6G 2B7 (403) 432-8822

APPENDIX B

LIFE SITUATION QUESTIONNAIRE

Religious affiliation:

☐ Protestant ☐ Jewish
☐ Catholic ☐ Other

Church interaction:

☐ devout (attends several times a month)
☐ moderate (Feast days)
☐ inactive

If you are single, do you date?

☐ no
☐ yes, rarely
☐ yes, once or twice a month
☐ yes, more frequently than twice a month

Are you working now? ☐ yes ☐ no

If yes: ☐ volunteer work ☐ for pay ☐ homemaker

If no, why not?

☐ don't want or need to
☐ can't find a job
☐ physical limitations
☐ repeated medical problems
☐ other (explain) _____

If you are working: average number of hours per week _____

Place of work: ☐ at home ☐ outside home

Name and location of employer: _____

Your occupation: _____

Annual income from earnings:

☐ less than \$3,000
☐ \$3,000 to \$6,000
☐ \$6,000 to \$10,000
☐ over \$10,000

How long have you been employed in this job? _____ years

What is your main source of support?

- ☐ own earnings
☐ earnings of spouse
☐ parents or other relatives
☐ Social Assistance
☐ public assistance (e.g., relief, welfare, etc.)
☐ insurance benefits
☐ other (explain) _____

Regardless of any other income, are you also receiving some form of public support, such as Social Assistance, or general relief?

☐ yes ☐ no

What kind of support? _____

Annual amount: \$ _____ per year

Are you in school now?

☐ no ☐ yes, full-time program
☐ yes, part-time program

Type of school:

☐ high school ☐ vocational-technical
☐ junior college or college ☐ business or trade school
☐ graduate or professional school
☐ correspondence program

What program or field of study are you in? _____

Name and location of school _____

How many years of education have you completed? _____

About how many hours per week do you usually spend in the following activities?

<input type="checkbox"/> TV or radio	<input type="checkbox"/> attending sports events
<input type="checkbox"/> reading	<input type="checkbox"/> group activities
<input type="checkbox"/> hobbies	<input type="checkbox"/> cards
<input type="checkbox"/> visiting in home	<input type="checkbox"/> talking books
<input type="checkbox"/> visiting away from home	

_____ other (explain) _____

 _____ other (explain) _____

How often do people come to see you?

_____ rarely _____ 1-2 times per week
 _____ 1-3 times per month _____ 3 or more times per week

How often do you get away from home for social or entertainment purposes (for example, to go shopping, visiting, or on an "outing")?

_____ rarely _____ 1-2 times per week
 _____ 1-3 times per month _____ 3 or more times per week

Are you an active member (that is, do you usually attend the meetings) of any organizations, such as church, a hobby or interest group, a social group, or business or professional organization?

_____ yes _____ no

If yes, please name the organizations below:

For the following activities, please check whether you are:

I = Independent (you need no help from another person)
 PD = Partly Dependent (you need some help)
 D = Dependent (someone else must do it for you)
 DA = Doesn't Apply

	I	PD	D	DA
Eating	_____	_____	_____	_____
Dressing	_____	_____	_____	_____
Personal Hygiene	_____	_____	_____	_____
Catheter Care	_____	_____	_____	_____
Bowel Program	_____	_____	_____	_____
Transfers	_____	_____	_____	_____
Wheelchair Use	_____	_____	_____	_____
Walking	_____	_____	_____	_____
Writing	_____	_____	_____	_____

	I	PD	D	DA
Typing	_____	_____	_____	_____
Telephone Use	_____	_____	_____	_____
Cooking	_____	_____	_____	_____
Housekeeping	_____	_____	_____	_____
Driving	_____	_____	_____	_____

What is your sitting tolerance per day?

_____ 0-3 hours

_____ 8-12 hours

_____ 4-7 hours

_____ more than 12 hours

Within the last two years, have you gone to a doctor for treatment of a medical problem of any kind (do not include routine checkups)?

_____ yes

_____ no

If yes, how many times?

_____ 1-3 times

_____ 4-10 times

_____ more than 10 times

Within the last two years, have you been hospitalized for any reason other than routine checkup?

_____ yes

_____ no

If yes, now many times?

For how many total days?

_____ 1-3 times

_____ less than one week

_____ 4-10 times

_____ one to four weeks

_____ more than 10 times

_____ more than four weeks

Within the last two years, have you gone to a professional person, such as a clergyman, family doctor, or mental health worker for help with a personal or emotional problem?

_____ yes

_____ no

If yes, how many times?

_____ 1-3 times

_____ 4-10 times

_____ more than 10 times

How satisfied are you with the following aspects of your present life?
(Circle the number that describes your feeling.)

1 = Very Satisfied

3 = Neutral

2 = Somewhat Satisfied

4 = Somewhat Dissatisfied

5 = Very Dissatisfied

	Very Satisfied		Neutral		Very Dissatisfied
Living Arrangements	1	2	3	4	5
Employment	1	2	3	4	5
Financial Means	1	2	3	4	5
Social Means	1	2	3	4	5
Sex Life	1	2	3	4	5
General Health	1	2	3	4	5

Have you ever requested or received services from any community agencies?

_____ yes

_____ no

If yes, which ones and when?

Date or Year

_____	_____
_____	_____
_____	_____

Suppose that a person's overall adjustment to spinal cord injury could be shown on a ladder having ten rungs, with the tenth rung representing the best possible adjustment and the first rung representing the worst possible. At what rung on that ladder would you place yourself to indicate your overall adjustment? (Circle the number that describes your adjustment).

1 2 3 4 5 6 7 8 9 10

Where on the ladder do you expect to be in five years?

1 2 3 4 5 6 7 8 9 10

_____ Check here if you would like to receive a report on the findings of this study.

_____ Check here if you would like to be paid for completing the questionnaire. (You can expect to receive payment by check in about six weeks.)

APPENDIX C

INDIVIDUAL INTERVIEW SCHEDULE

Date: _____

Interviewer: _____

INDIVIDUAL INTERVIEW SCHEDULE*

* Name: _____

* Date of Injury: _____

1. How were you injured? (Record Narrative)

<u>Transportation</u>	<u>Personal Assault</u>	<u>Sport</u>	<u>Other</u>
<u> </u> Auto	<u> </u> Gunshot	<u> </u> Water	<u> </u> Fall
<u> </u> Motorcycle	<u> </u> Stabbing	<u> </u> Winter	<u> </u> Falling Object
<u> </u> Pedestrian	<u> </u> Blunt Trauma	<u> </u> Field	<u> </u> Other _____
<u> </u> Other	<u> </u> Other	<u> </u> Other	

2. (Interviewer judgement: The subject's involvement in the injury was passive, active, indeterminant (see supplemental instructions for definition).

3. What hospital were you taken to right after your injury? Name:

4. Were you later taken to other hospitals? Name(s):

5. (Initial hospitalization: rehabilitation center, not a comprehensive rehabilitation hospital (see supplemental instructions)). How long were you in hospital altogether?

* Adapted from: University of Minnesota
Dept. of Physical Medicine & Rehabilitation
Crewe, Athelstan & Krumberger, 1979

- [illegible]

13. Did you have some medical complications during your first hospitalization?

- | | |
|---|--|
| <input type="checkbox"/> no | <input type="checkbox"/> vascular |
| <input type="checkbox"/> musculoskeletal | <input type="checkbox"/> urologic |
| <input type="checkbox"/> neurologic | <input type="checkbox"/> psychological |
| <input type="checkbox"/> respiratory | <input type="checkbox"/> decubiti |
| <input type="checkbox"/> gastrointestinal | <input type="checkbox"/> allergic reaction |

14. What family members spent the most time with you at the time of your injury?

- | | |
|---|--|
| <input type="checkbox"/> no one in particular | <input type="checkbox"/> sibling(s) |
| <input type="checkbox"/> mother | <input type="checkbox"/> children |
| <input type="checkbox"/> father | <input type="checkbox"/> other relatives _____ |
| <input type="checkbox"/> spouse | |

15. How did they react to your injury? (Record Narrative)

16. In what way, if any, did your injury change your relationship with them? (Record Narrative)

17. TO SPOUSE: Did you receive the information and/or counselling which you needed? (Record Narrative)

- | |
|---|
| <input type="checkbox"/> Yes - received adequate information and counselling |
| <input type="checkbox"/> Received information but not adequate counselling or support |
| <input type="checkbox"/> Received some help, but not enough |
| <input type="checkbox"/> No |
| <input type="checkbox"/> Didn't need information or counselling |
| <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Don't know |

18. Can you think of any turning points or anything that happened in the hospital that seemed to have a major affect on your recovery or in your feelings about what happened to you? (Record Narrative)

- | | |
|---|---|
| <input type="checkbox"/> no | <input type="checkbox"/> medical |
| <input type="checkbox"/> don't remember | <input type="checkbox"/> personal-interpersonal |

19. Did you even think of suicide during your initial hospitalization?

- | |
|---|
| <input type="checkbox"/> no |
| <input type="checkbox"/> yes - once or twice |
| <input type="checkbox"/> yes - vaguely thought about it |
| <input type="checkbox"/> yes - seriously considered suicide |
| <input type="checkbox"/> yes - actually planned suicide |
| <input type="checkbox"/> other _____ |

20. Have you had any thoughts about suicide since then? (Record Narrative)

- ☐ no
- ☐ yes - once or twice
- ☐ yes - vaguely thought about it
- ☐ yes - seriously considered suicide
- ☐ yes - actually planned suicide
- ☐ other _____

21. How ready were you for leaving the hospital physically? (Record Narrative)

- ☐ as ready as possible
- ☐ ready except for _____
- ☐ not ready physically
- ☐ don't remember

22. How ready were you for leaving the hospital mentally? (Record Narrative)

- ☐ well prepared
- ☐ hospital environment "ideal" - real world a shock
- ☐ overly anxious to go - may have left too soon
- ☐ reluctant to leave hospital - had to be pushed
- ☐ poorly prepared
- ☐ other _____
- ☐ don't remember

23. Can you tell me the ways in which the rehabilitation staff could have better prepared you on leaving? (Record Narrative)

- ☐ no - everything possible was done
- ☐ yes - more home visits or social excursions before leaving
- ☐ yes - more or better psychological preparation
- ☐ yes - more physical preparation
- ☐ yes - other _____
- ☐ no answer

24. When you were leaving the hospital, did you expect to return to school or work soon?

- ☐ no, ☐ yes, in 1-2 months,
- ☐ yes, definite plans for some future time.

25. When you were leaving the hospital, did you expect to get out of the house often and to see friends and do things socially?

- ☐ no ☐ yes

26. When you were leaving the hospital, did you expect to spend a lot of time in bed?

☐ no

☐ yes

27. Do you think the staff at the hospital expected the same things from you? (Record Narrative)

☐ no

☐ yes

☐ no sense of staff expectations

28. Do you think your family expected generally the same things from you as you expected of yourself? (Record Narrative)

☐ no

☐ yes

☐ no sense of family expectations

29. * ADL's ☐ personal ☐ mobility ☐ communication
☐ housekeeping ☐ driving

Are you taking care of yourself (ADL's) any more or less than when you left the hospital? (Record Narrative for each of the above).

☐ no change

☐ more - I am now doing _____ for
 myself which I didn't then.

☐ less - I no longer do _____ for
 myself

☐ mixed gains and losses

30. How do you feel having to depend on other people to do things for you? (ADL's) (Record Narrative and interview check)

☐ enjoy having others care for me

☐ feel OK - no special problems

☐ was hard at first, but got used to it

☐ not too bad except for one or two specific areas

☐ moderate discomfort

☐ resentful of dependency. Very uncomfortable

☐ Other _____

☐ Not applicable

31. What things, if any, are hardest for you to accept help with?

☐ feeding

☐ urinary functioning or appliances

☐ bowel program

☐ bathing or personal hygiene

☐ dressing

☐ wheelchair mobility

☐ transportation outside home

☐ transfers

☐ other _____

☐ none of the above

32. Have you have regular check-ups since your injury?

☐ no

☐ yes - at least annually at

☐ yes - at least annually with local physician or hospital

☐ have had some check-ups, but not regularly

33. Have you been hospitalized for any medical problems since your discharge?

☐ no

☐ yes

If yes: When ☐ How long ☐ For what reason ☐
 When ☐ How long ☐ For what reason ☐
 When ☐ How long ☐ For what reason ☐

34. Have you had any medical problems since your discharge which did not require hospitalization?

☐ no

☐ yes

If yes: When ☐ What ☐
 When ☐ What ☐
 When ☐ What ☐

As appropriate

35. Have your medical problems interfered with your ability to work?
 (Record Narrative)

☐ no

☐ Yes

36. Do you have any continuing pain? (Record Narrative)

☐ no

☐ yes - does not interfere with functioning

☐ yes - limits functioning

If yes: Source of pain. (Record Narrative)

☐ paresthesias

☐ headaches

☐ not applicable

☐ contractures

☐ other ☐

37. Do you have any continuing problems with spasticity? (Record Narrative)

☐ no

☐ yes, does not interfere with functioning

☐ yes, interferes with functioning

38. Are you currently taking any medications

☐ no

☐ yes, For what reasons? (Record Narrative)

Can you tell me what they are and how frequently you take them?

They are: 1. ☐ Dose ☐
 2. ☐ Dose ☐
 3. ☐ Dose ☐
 4. ☐ Dose ☐

39. LIVING ARRANGEMENTS

* Present living arrangements

* Level of satisfaction

Where did you live when you first left the hospital? After than, etc.

(see questions) (Record in months)

1st 2nd 3rd 4th

___	___	___	___	alone (I)
___	___	___	___	with hired attendant (I)
___	___	___	___	with spouse or friends (I)
___	___	___	___	with parents or other relatives (D)
___	___	___	___	nursing home (D)
___	___	___	___	dormitory or boarding home (I)
___	___	___	___	other _____

40. You live with your spouse and (children). Do you have any assistance from anyone else?

___ family
 ___ attendant
 ___ friend

41. If you had a choice, would you make any change in your present living situation?

___ no
 ___ yes What would you change?

What prevents you from making this change?
 (Record Narrative)

WORKING - GO TO PAGE 13

42. IF NOT WORKING

* You indicated on your questionnaire that you are not working because *. Could you tell me something about that? (Record Narrative)

43. What were your expectations in regard to finding employment?

44. What type of job did you have immediately prior to your injury?
 (Record Narrative)

45. IF NO Have you actively looked for work at any time since your injury?

no yes

IF YES How did you go about it? (Record Narrative)

- waited for something to appear
- worked with vocational counsellor
- worked with school placement
- worked with private employment agency
- followed up ads
- other
- not applicable

46. Did you have any success? (Record Narrative)

- yes, found job
- was offered job but didn't take it
- no
- not applicable

47. How long did you continue looking?

- less than 1 month
- 1 - 6 months
- 6 months - 1 year
- 1 - 2 years
- longer than 2 years
- not applicable

48. Why did you stop looking? (Record Narrative)

- decide there wasn't any use
- became depressed or discouraged
- found other ways to use my time
- people suggested that I stop
- found a job
- not applicable

49. Given a choice, would you prefer to be working, or do you prefer things the way they are? (Record Narrative)

- prefer things the way they are
- prefer to be working

50. Do you expect to be working in the near future? (Record Narrative)

 no yes

51. Do you think your family expects you to be working in the near future? (Record Narrative)

 no yes

GO TO PAGE ____ IF EMPLOYMENT NOT REALISTIC

52. What types of conditions would you like to have in a job? (Record Narrative)

type of job _____ convenience to house _____
 house _____ other _____
 salary _____

53. Have you worked anywhere since your injury? Most recent post injury job 1

_____ no _____ yes

IF NO, TURN TO PAGE ____

54. What was the job title?

What exactly did you do on this job? (Record Narrative)

55. How many hours per week did you work? ____ hours

56. What was your income? _____ dollars per _____

57. When did you work there? _____ start _____ end

58. How long were you unemployed before finding this job? _____ months

59. What were the reasons for your not working during this time?
 (Record Narrative)

60. What did you do with your time while you were unemployed before you found this job? (Record Narrative)

61. How did you find this job?

_____ on my own _____ friend or relative _____ DVR
 _____ employment service _____ college or school placement
 _____ same place as pre-injury job _____ other _____

62. How long did you actually look for this job? _____ months

63. How many jobs did you apply for before you got this job? ____
number of jobs
64. Were there any special changes made on the job for you to do this work? (Record Narrative)
☐ no ☐ modified hours
☐ architectural barriers ☐ lower production standards
☐ duty modifications ☐ other _____
65. Did you come up against any problems in working? (Record Narrative)
☐ no ☐ limited sitting tolerance
☐ didn't pay well enough ☐ transportation problems
☐ conflict with boss or workers ☐ other _____
☐ couldn't work fast enough
66. What do you consider to have been the good things about that job?
(Record Narrative)
67. What do you consider to have been the bad things about that job?
(Record Narrative)
68. All in all, how satisfied were you with that job? (Record Narrative)
69. Why did you leave that job? (Record Narrative)
70. Have you had any other job since your injury?
☐ no ☐ yes
IF NO, GO TO PAGE _____

1. What was the job title? Most recent post injury job 2
2. What exactly did you do on this job? (Record Narrative)
3. How many hours per week did you work? hours
4. What was your income? dollars per
5. When did you work there? start end
6. How long were you unemployed before finding this job? months
7. What were the reasons for your not working during this time?
(Record Narrative)
8. What did you do with your time while you were unemployed before you
found this job? (Record Narrative)
9. How did you find this job?
 on my own friend or relative DVR
 employment service college or school placement
 same place as pre-injury job other
10. How long did you actually look for this job? months
11. How many jobs did you apply for before you got this job?
number of jobs
12. Were there any special changes made on the job for you to do this
work? (Record Narrative)
 no modified hours
 architectural barriers lower production standards
 duty modifications other
13. Did you come up against any problems in working? (Record Narrative)
 no limited sitting tolerance
 didn't pay well enough transportation problems
 conflict with boss or workers other
 couldn't work fast enough

14. What do you consider to have been the good things about that job?
(Record Narrative)
15. What do you consider to have been the bad things about that job?
(Record Narrative)
16. All in all, how satisfied were you with that job? (Record Narrative)
17. Why did you leave that job? (Record Narrative)
18. Have you had any other job since your injury?
 ___ no ___ yes

WORKING

71. What is the title of your job?
72. What exactly to do you do on your job? (Record Narrative)
73. How many hours per week do you work? _____ hours distrib.
74. You stated that your income was _____ dollars per _____ distrib.
75. When did you start working on this job? _____ date
76. Was a job waiting for you on discharge? _____ months
(if no, go to 79)
77. What were your reasons for not working? (Record Narrative)
78. What did you do with your time while your were unemployed before you found this job? (Record Narrative)
79. How did you find this job? (Freq. count.)
- | | |
|---|--|
| <input type="checkbox"/> on my own | <input type="checkbox"/> college or school placement |
| <input type="checkbox"/> friend or relative | <input type="checkbox"/> same place as pre-injuiry job |
| <input type="checkbox"/> CPA | <input type="checkbox"/> other _____ |
| <input type="checkbox"/> employment service | |
80. Were there any special changes made on the job for you to do this work? (freq. + narr.) (Record Narrative)
- | | |
|---|---|
| <input type="checkbox"/> no | <input type="checkbox"/> modified hours |
| <input type="checkbox"/> architectural barriers | <input type="checkbox"/> lower production standards |
| <input type="checkbox"/> special equipment | <input type="checkbox"/> other _____ |
| <input type="checkbox"/> duty modifications | <input type="checkbox"/> washroom |
81. A) Have you come up against things that you consider a problem in working? (Record Narrative)
- | |
|---|
| <input type="checkbox"/> no |
| <input type="checkbox"/> can't get a job I really like |
| <input type="checkbox"/> conflict with boss or workers |
| <input type="checkbox"/> architectural problems |
| <input type="checkbox"/> can't perform some required duties |

- ☐ can't perform as fast as I would like
- ☐ limited sitting tolerance
- ☐ transportation problems
- ☐ other _____ (freq. + narr.)

B) What kind(s) of transportation do you use?

- ☐ drive own auto or van
- ☐ someone drives me in auto or van
- ☐ special systems (e.g. Handicabs)
- ☐ public transportation
- ☐ none
- ☐ other _____

C) If drive, are you able to transfer and handle your chair independently?

- ☐ yes, independent with auto
- ☐ yes, independent with van
- ☐ no, need some assistance

82. What do you consider to be the good things about your job? (Record Narrative)

- | | |
|--|---|
| <input type="checkbox"/> salary | <input type="checkbox"/> people you work with (other than boss) |
| <input type="checkbox"/> work on own | <input type="checkbox"/> responsibility, chance for advancement |
| <input type="checkbox"/> easily done | <input type="checkbox"/> other points |
| <input type="checkbox"/> fringe benefits | |

83. What do you consider to be the bad things about your job? (Record Narrative)

- | | |
|--|--|
| <input type="checkbox"/> too routine | <input type="checkbox"/> little chance for advancement |
| <input type="checkbox"/> salary too low | <input type="checkbox"/> people around you |
| <input type="checkbox"/> restricted environ- | <input type="checkbox"/> other points |
| <input type="checkbox"/> ment once in building | |

84. All in all, how satisfied are you with your job? (Record Narrative)

0	1	2	3	4	5	6
Extremely	Fairly	A Little	Satisfied	Very	Extremely	Perfect
Unsatis-	Unsatis-	Satisfied		Satisfied	Satisfied	
fied	fied					

85. Do you expect to be making any changes in your working status in the near future? (Record Narrative)

86. Do you feel that your family expects you to continue working?
(Record Narrative)

87. Have you discussed your working or not working with your wife?
(Record Narrative)

___ no ___ yes (address wife)

GO TO 106 PAGE P. 16

Most recent post injury job 2 REPEAT

88. What was the job title?

89. What exactly did you do on this job? (Record Narrative)

90. How many hours per week did you work? ___ hours

91. What was your income? ___ dollars per ___

92. When did you work there? ___ start ___ end

93. How long were you unemployed before finding this job? ___ months

94. What were the reasons for your not working during this time?
(Record Narrative)

95. What did you do with your time while you were unemployed before you found this job? (Record Narrative)

96. How did you find this job?

___ on my own ___ friend or relative ___ DVR
___ employment service ___ college or school placement
___ same place as pre-injury job ___ other _____

97. How long did you actually look for this job? ___ months

98. How many jobs did you apply for before you got this job? ___
number of jobs

99. Were there any special changes made on the job for you to do this work? (Record Narrative)
- | | |
|---|---|
| <input type="checkbox"/> no | <input type="checkbox"/> modified hours |
| <input type="checkbox"/> architectural barriers | <input type="checkbox"/> lower production standards |
| <input type="checkbox"/> duty modifications | <input type="checkbox"/> other _____ |
100. Did you come up against any problems in working? (Record Narrative)
- | | |
|--|--|
| <input type="checkbox"/> no | <input type="checkbox"/> limited sitting tolerance |
| <input type="checkbox"/> didn't pay well enough | <input type="checkbox"/> transportation problems |
| <input type="checkbox"/> conflict with boss or workers | <input type="checkbox"/> other _____ |
| <input type="checkbox"/> couldn't work fast enough | |
101. What do you consider to have been the good things about that job? (Record Narrative)
102. What do you consider to have been the bad things about that job? (Record Narrative)
103. All in all, how satisfied were you with that job? (Record Narrative)
104. Why did you leave that job? (Record Narrative)
105. Have you had any other job since your injury?
- ☐ no ☐ yes

PRE INJURY HISTORY

106. What is the last job you had before your injury? (If no pre-injury work, go to page 18)
107. What was the job title? _____ self employed
108. What exactly did you do on this job? (Record Narrative)
109. How many hours per week did you work? _____ hours
110. What was your income? _____ dollars per _____

111. When did you find work there? _____ start _____ end
112. How did you find this job?
_____ on my own _____ college or school placement
_____ friend or relative _____ other _____
_____ Canada Manpower
_____ employment service
113. How long did you actually look for this job? _____ months
114. How many jobs did you apply for before you got this job?
_____ number of jobs applied for
115. Did you come up against any problems in working? (Record Narrative)
_____ no
_____ didn't pay well enough
_____ conflict with boss or workers
_____ didn't like the job
_____ couldn't work fast enough
_____ couldn't perform required duties
_____ transportation problems
_____ other _____
116. What do you consider to have been the good things about that job?
(Record Narrative)
117. What do you consider to have been the bad things about that job?
(Record Narrative)
118. All in all, how satisfied were you with that job? (Record Narrative)
119. Why did you leave that job? (Record Narrative)
120. Had you planned to make that job or work like it your career?
(Record Narrative)
_____ no _____ yes
121. Did you have any other jobs before your injury? _____ no _____ yes
(If no, go to page _____)

122. "Repeat for all other pre-injury jobs".

If yes: Title:
 Duties:
 Dates:
 Salary:
 Reason for leaving:
 Description of gaps in employment:

(repeat for any further pre-injury jobs)

GENERAL INFORMATION ON COMMUNITY

123. Were you ever a CPA client?

___ no ___ yes

124. If no, Have you ever had any testing related to going to work? ___ no ___ yes

Where

When

125. Have you ever talked to a counsellor or anyone else about going to work? ___ no ___ yes

Who

Where

When

126. If yes, What did the services do for you? (Record Narrative)

127. How could they have been made better for you?
 (Record Narrative)

See LSQ

128. Are you getting any kind of public support or financial assistance?

129. If receiving support

What kind of support are you getting?

130.

How much do you get? _____ \$
 _____ not known

131.

How do you feel about getting this assistance? (Record Narrative)

132.

How long do you think it will be necessary to receive support?
 _____ time

133. If not receiving support

Have you ever received any public support since your injury?
 ____ no ____ yes

134.

If yes, When? _____ start _____ end

Why are you not receiving it now? (Record Narrative)

135.

How do you feel about the idea of receiving public assistance? (Record Narrative)

136.

Do you feel it will ever be necessary for you in the future? (Record Narrative)
 ____ no ____ yes

Educational History (markpoint of injury)

137. School	Major or Program	Dates	Degree or Certificate	Satisfaction
-------------	------------------	-------	-----------------------	--------------

SEE L.S.Q.

138. How did you spend to-day? (Record main activity)
(card)

[]	Hours 7	5
	8	6
	9	7
	10	8
	11	9
	12	10
	1	11
	2	12
	3	1
	4	2

139. How would you rate your social life before your injury? (Record Narrative)

(card) (is this any different from a normal day now)

[]

___ similar to present social life

___ more active than now

___ less active than now

___ other _____

140. What was your social life like for the first six months to 1 year after you came out of the hospital for the first time?
(Record Narrative)

140a. How often would you see people after than your wife at that time?

140. ___ 1) isolated

___ 2) limited to spouse and close family

___ 3) one or two friends only

___ 4) combination of 2 & 3 above

___ 5) interacted with a number of people

___ 6) number of friends dwindled

___ 7) Other _____

- 140 a. ☐ daily
☐ every other day
☐ twice a week
☐ once week
☐ once every 2 weeks
☐ one per month
☐ other

141. How often did you go out socially during this time?
 (card)
 []

- ☐ Stayed at home all the time
☐ Went out rarely
☐ Went out 1-3 times per month
☐ Went out 1-2 times per week
☐ Went out 3 or more times per week

142. Why didn't you go out more often?

- ☐ No
☐ Some mild reservations
☐ Yes, about going to some places
☐ Yes, reluctant to go almost anywhere
☐ Other _____

143. What is your social life like
 now? (Record Narrative)

143a. How often do you see people
 other than at work now?

143. ☐ 1) isolated
☐ 2) limited to spouse and close family
☐ 3) one or two friends only
☐ 4) combination of 2 & 3 above
☐ 5) interacted with a number of people
☐ 6) number of friends dwindled
☐ 7) Other _____

- 143a. ☐ daily
☐ every other day
☐ twice a week
☐ once week
☐ once every 2 weeks
☐ one per month
☐ other

144. How often do you go out socially now?

(Card)

[]

- ☐ Stay at home all the time
- ☐ Out rarely
- ☐ Out 1-3 times per month
- ☐ Out 1-2 times per week
- ☐ Out 3 or more times per week

145. Presently, why don't you go out more often?

- ☐ No
- ☐ Some mild reservations
- ☐ Yes, about going to some places
- ☐ Yes, reluctant to go almost anywhere
- ☐ Other

146. Who do you consider really close to you now?

- no one — yes
not sure wife only

147. If there is someone, identify him/her

- ☐ Spouse ☐ Same sex friend(s)
☐ Offspring ☐ Opposite sex friend(s)
☐ Parent(s) ☐ Other _____
☐ Other parents

148. Did you know them before your injury? Whose's friends His
(other than spouse) Hers

- no yes There's

149. How recently have you seen them?

- ☐ Within the past week ☐ Longer than the past year
☐ Within the past month ☐ Other _____
☐ Within the past year

150. Are most of your current friends people that you have know from
before your injury or are they people that you have met since your
injury?

- ```

pre post

```

151. Have you ever belonged to an organization for peoples with disabilities?

- no                      yes



152. Why or Why not?

- ☐ Don't know of any such organizations
- ☐ Don't enjoy being with handicapped people
- ☐ Too busy
- ☐ Not a "joiner"
- ☐ Feel comfortable with disabled people
- ☐ Friend or acquaintance invited me to join
- ☐ I enjoy their meetings and/or activities
- ☐ Want to contribute toward their goals
- ☐ Combination
- ☐ Other \_\_\_\_\_

153. You have been married \_\_\_\_\_ years  
       \_\_\_ Before injury                      \_\_\_ After injury

154. Is this your first marriage?  
       \_\_\_ no                      \_\_\_ yes

155. Where did you meet each other?

156. Interviewer Judgement:

What are the main benefits the subject gets out of the marriage?

- ☐ Companionship
- ☐ Financial
- ☐ Psychological support
- ☐ Children
- ☐ Physical convenience (e.g. help with adl's)
- ☐ Avoid loneliness
- ☐ Other \_\_\_\_\_
- ☐ No response

157. How happy do you consider your marriage to be?  
 (Record Narrative)

157a. If I were to have asked you one year ago, how happy you were with your marriage, how would you have rated it?

157.

|            |                            |       |                            |               |
|------------|----------------------------|-------|----------------------------|---------------|
| 1          | 2                          | 3     | 4                          | 5             |
| Very Happy | More Unhappy<br>Than Happy | Happy | More Happy<br>Than Unhappy | Very<br>Happy |



157a.

|            |                            |       |                            |               |
|------------|----------------------------|-------|----------------------------|---------------|
| 1          | 2                          | 3     | 4                          | 5             |
| Very Happy | More Unhappy<br>Than Happy | Happy | More Happy<br>Than Unhappy | Very<br>Happy |

158. Interviewer Judgement

Rate marriage of 1-5 scale

- ☐ 1) very unhappy
- ☐ 2) somewhat unsatisfying
- ☐ 3) like most marriages
- ☐ 4) somewhat satisfying
- ☐ 5) very happy

159. You have children.      Ages       Sex   
                                                                                       
                                                                                    

160. How close to you feel  
to your wife?

160a. If I were to have asked you  
one year ago, how close you  
felt to your spouse, how would  
you have rated it?

160.

- ☐ 1) Very much in tune, sharing duties and work, spend time together
- ☐ 2) Friendly, living together but different views of the same situation, spend time together
- ☐ 3) Don't talk to each other very much, don't share duties and responsibilities
- ☐ 4) Cold, avoid each other as much as possible
- ☐ 5) Conflicts, potential breakup, no interactions, hostile
- ☐ #) Other (specify) \_\_\_\_\_
- ☐ U) Unknown

160a.

1. Very much in tune with each other, sharing duties and work, spend time together.
2. Friendly, not completely understanding each other's needs, living together but different perceptions of the same situation, spend time together.
3. Move about the same house with little or no communication, don't share duties and responsibilities.
4. Cold, aloof, inaccessible, remote and uncommunicative.
5. Conflicts, potential breakup, spend no time together, no interactions, hostile.



161. Since your SCI, has the importance of sex changed in your life?

|           |           |        |           |           |
|-----------|-----------|--------|-----------|-----------|
| 1         | 2         | 3      | 4         | 5         |
| Not       | Less      | No     | More      | Very      |
| Important | Important | Change | Important | Important |

162. What changes, if any, have you made in the nature of your sexual activities since your injury?

(card)

[ ]

- a) ☐ No changes
- b) ☐ No sexual activity
- c) ☐ Reduced frequency of intercourse
- d) ☐ Increased frequency of intercourse
- e) ☐ Use of mechanical aids (vibrators, dildos, etc.)
- f) ☐ Different positions for intercourse
- g) ☐ Alternative methods of stimulation (masturbation, oral sex, etc.)
- h) ☐ Change in preferred sex of partner
- i) ☐ Other (specify) \_\_\_\_\_

163. If you are not, check as many reasons as are appropriate:

(card)

[ ]

- a) ☐ Religious or moral reasons
- b) ☐ Lack of contracts or partners
- c) ☐ Lack of privacy
- d) ☐ Lack of money
- e) ☐ My lack of sexual interest
- f) ☐ My partner's lack of sexual interest
- g) ☐ My lack of information
- h) ☐ My partner's lack of information
- i) ☐ My fear (health concerns, rejection, self consciousness, etc.)
- j) ☐ My partner's fear
- k) ☐ Problem with erections (male only)
- l) ☐ Physical difficulty in carrying out sex acts
- m) ☐ I am not sexually desirable
- n) ☐ I don't like my body
- o) ☐ SCI related physical problems (infections, pain, contractures, spasticity, urinary, bowel or skin problems, etc.)
- p) ☐ Non-SCI related physical problems
- q) ☐ I am too young
- r) ☐ I am too old
- s) ☐ Other (specify) \_\_\_\_\_

When seems finished, ask 164.





164. Write in the letter of the single most important of the above reasons.

U Unknown

X N/A

165. Since your SCI have you received helpful sexual advice, information, counseling or training?

Y Yes

N No

U Unknown

166. What were the sources of this helpful sexual information?

[ ]

a) ☐ Received no information

b) ☐ Doctor

c) ☐ Nurse

d) ☐ Therapist

e) ☐ Counselor

f) ☐ Social worker

g) ☐ Written material

h) ☐ Other inpatients

i) ☐ Former patients

j) ☐ Spouse, friend other non-hospital person

k) ☐ Work shops

l) ☐ Other (specify) \_\_\_\_\_

167. What changes, if any, would you like to make to improve your sex life? (Record Narrative)

168. What do you consider to be your most important thing you've done since your injury? (Record Narrative)

☐ personal adjustment ☐ ADL independence

☐ family or relationship ☐ nothing

☐ work or school ☐ other \_\_\_\_\_

☐ physical accomplishment or return

169. Has anything happened to you that would not have happened if you had not been injured? (Record Narrative)

☐ no

☐ yes, personal growth

☐ yes, growth in relationships

☐ yes, new vocational goals

☐ yes, other \_\_\_\_\_

You might have felt right after your injury that you had lost everything that was important to you as a person when you considered that you couldn't walk and how your life would change. I would like to ask you how you feel about your injury now. If you were to assign a percentage figure, what would you say it would be, if, for example, 100% would mean that you have lost everything that is important to you in life, and if you feel you have lost nothing, it would be 0%.



170. \_\_\_\_\_ % So you mean you have lost all but (100 answer) % of what is important to you in life? (feedback check - e.g.)
171. One of the things we are trying to do by asking these kinds of questions is to piece together a picture of how a person adjusts emotionally to spinal cord injury. We would like you to remember how you were feeling soon after your injury and tell us how these feelings have changed over the years. (Record Narrative).  
Right after injury, how did you feel?
172. Can you think of any experience(s) since your injury which might be described as "turning points" in your adjustment? (Record Narrative)
173. What things about life give you the most pleasure? (Record Narrative)
- |                                             |                                      |
|---------------------------------------------|--------------------------------------|
| <input type="checkbox"/> nothing            | <input type="checkbox"/> hobbies     |
| <input type="checkbox"/> relationships with | <input type="checkbox"/> radio or TV |
| <input type="checkbox"/> family or friends  | <input type="checkbox"/> religion    |
| <input type="checkbox"/> work               | <input type="checkbox"/> other _____ |
| <input type="checkbox"/> study or learning  |                                      |
174. What are your greatest sources of frustration? (Record Narrative)
- |                                               |                                                      |
|-----------------------------------------------|------------------------------------------------------|
| <input type="checkbox"/> loneliness.          | <input type="checkbox"/> boredom                     |
| <input type="checkbox"/> physical limitations | <input type="checkbox"/> sexual deprivation          |
| <input type="checkbox"/> lack of money        | <input type="checkbox"/> living arrangements or lack |
| <input type="checkbox"/> poor health          | <input type="checkbox"/> of privacy                  |
| <input type="checkbox"/> other _____          |                                                      |
175. What things in life are most important to you? (Record Narrative)
176. Has this changed from before your accident? (Record Narrative)
177. Some people with spinal cord injury have told us that they enjoy imagining themselves doing things that they used to do which are now either impossible or are somewhat changed - things like running, playing football, dancing or having sexual intercourse. These fantasies are very vivid, and for some people may almost seem real. Have you had experiences like this? (Record Narrative)
178. If yes, do you sometimes start fantasies or daydreams on purpose just for the pleasure of it?
- |                             |                              |                                         |
|-----------------------------|------------------------------|-----------------------------------------|
| <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> not applicable |
|-----------------------------|------------------------------|-----------------------------------------|



179. What are your favorite topics for these daydreams? (Record Narrative)

\_\_\_ not applicable (none or one only)

180. If your dreams at night, are you able bodied or disabled?

\_\_\_ ab

\_\_\_ not aware of dreams

\_\_\_ disabled

\_\_\_ other

\_\_\_ sometimes, ab, sometimes disabled

181. How do you feel about your body?

\_\_\_ very satisfied

\_\_\_ somewhat satisfied

\_\_\_ neutral

\_\_\_ somewhat dissatisfied

\_\_\_ very dissatisfied

\_\_\_ unsure

182. Where would you like to be and what would you like to be doing 10 years from now? (Record Narrative)

\_\_\_ has specific and potentially realistic plans

\_\_\_ would like to be essentially the same as present

\_\_\_ has definite but highly unlikely answer (i.e.: be a millionaire or completely recovered).

\_\_\_ unwilling or unable to answer

\_\_\_ other

183. Do you think religion has played a part in your overall adjustment to your injury? (Record Narrative) (see LSQ)

184. Can you think of anything that we haven't talked about that you think would be important for us to know in understanding your overall adjustment to your injury? (Record Narrative)

185. We talk about adjusting to disability, what does this mean to you?

186. How adjusted do you think you are? (scale qual.)

1    2    3    4    5    6    7    8    9    10





APPENDIX D

INTERVIEW SCHEDULE FOR SIGNIFICANT OTHERS



INTERVIEW SCHEDULE FOR SIGNIFICANT OTHERS

1. Name of SCI person

2. Name of significant other

3. Relationship

\_\_\_\_\_ spouse

\_\_\_\_\_ parent

\_\_\_\_\_ sibling

\_\_\_\_\_ offspring

\_\_\_\_\_ natural

\_\_\_\_\_ adopted

\_\_\_\_\_ other

4. IF THE RELATIONSHIP HAS NOT BEEN LIFE LONG

How long have you known \_\_\_\_\_/

5. Do you and \_\_\_\_\_ live together?

\_\_\_\_\_ yes \_\_\_\_\_ no







6. Did you expect \_\_\_\_\_ to be able to return to school or work?  
 \_\_\_\_\_ yes \_\_\_\_\_ no

7. What are your feelings about it now?

8. Have you ever discussed it?

9. How close was your relationship with \_\_\_\_\_ before he/she was hurt?

10. About how much time did you spend together?

\_\_\_\_\_ hours a day

\_\_\_\_\_ hours a week

\_\_\_\_\_ other \_\_\_\_\_

11. What sort of things did you do together?

\_\_\_\_\_ dance

\_\_\_\_\_ work

\_\_\_\_\_ visit

\_\_\_\_\_ play cards

\_\_\_\_\_ go out

\_\_\_\_\_ household chores

\_\_\_\_\_ chorus

\_\_\_\_\_ church





12. Did things change between you and \_\_\_\_\_ as a result of the injury?

\_\_\_\_\_ yes

\_\_\_\_\_ no

IF YES

12a. In what ways?

\_\_\_\_\_ closer

\_\_\_\_\_ better

\_\_\_\_\_ no change

\_\_\_\_\_ drifted apart

\_\_\_\_\_ more dependent

13. Do you think that \_\_\_\_\_ felt different about things between you and he?

\_\_\_\_\_ yes

\_\_\_\_\_ no

IF YES

13a. In what ways?.

14. What sort of person was \_\_\_\_\_ before his injury?

\_\_\_\_\_ happy go lucky

\_\_\_\_\_ quiet

\_\_\_\_\_ hard worker

\_\_\_\_\_ athletic

\_\_\_\_\_ loving

\_\_\_\_\_ accepting

15. What changes have you noticed in \_\_\_\_\_'s personality since the injury?

\_\_\_\_\_ no change

\_\_\_\_\_ more \_\_\_\_\_ less energetic

\_\_\_\_\_ more \_\_\_\_\_ less talkative

\_\_\_\_\_ more \_\_\_\_\_ less happy

\_\_\_\_\_ easier \_\_\_\_\_ harder to get along with

\_\_\_\_\_ more \_\_\_\_\_ less sociable



16. Did \_\_\_\_\_'s injury change his vocational plans?  
\_\_\_\_\_ yes \_\_\_\_\_ no

IF YES

16a. What changes did his injury make?

\_\_\_\_\_ no job \_\_\_\_\_ altered plans  
\_\_\_\_\_ change job \_\_\_\_\_ don't know

17. Did \_\_\_\_\_'s injury change his marriage plans?  
\_\_\_\_\_ yes \_\_\_\_\_ no

IF YES

17a. What changes did his injury make?

\_\_\_\_\_ didn't get married \_\_\_\_\_ got married

18. Did \_\_\_\_\_'s injury change his social life?  
\_\_\_\_\_ yes \_\_\_\_\_ no

IF YES

18a. What changes did his injury make?

\_\_\_\_\_ friends come to see him more often  
\_\_\_\_\_ some friends don't come to see him  
\_\_\_\_\_ less of a social life than before  
\_\_\_\_\_ no change  
\_\_\_\_\_ doesn't discuss it  
\_\_\_\_\_ he does different things than before



19. Did the injury place a burden on you financially?

\_\_\_\_\_ yes \_\_\_\_\_ no

20 You've just said that \_\_\_\_\_'s injury resulted in a few changes in his life. Do you think of these things as being positive or negative changes.

\_\_\_\_\_ positive \_\_\_\_\_ negative \_\_\_\_\_ mixed

21. Do you think that these changes could have been avoided or made different in any way?

\_\_\_\_\_ yes \_\_\_\_\_ no

22. Can you think of any particular turning point that made a difference in how you adjusted to \_\_\_\_\_'s injury?

23. Can you think of any particular turning point that made a difference in how \_\_\_\_\_ adjusted to his injury?

24. How was your life changed by the injury?

|                          |                                 |
|--------------------------|---------------------------------|
| _____ Stay at home more  | _____ Longer hours              |
| _____ Take care of _____ | _____ Learned to be depended on |
| _____ Go out to work     | _____ Not free to come and go   |

25. How much time do you now spend together?





26. Did you have to give up any activities?

IF SPOUSE

27. What made you decide to stay together after \_\_\_\_\_'s injury?

IF SPOUSE WITH CHILDREN

28. How have your children responded to \_\_\_\_\_'s injury?  
(narrative)

\_\_\_\_\_ they come to visit

\_\_\_\_\_ they call

\_\_\_\_\_ very helpful

\_\_\_\_\_ they don't call or visit

\_\_\_\_\_ not very helpful

\_\_\_\_\_ adjusted well



PART 2

1. Before \_\_\_\_\_'s injury, who made the decision in your family?

2. Was there any change in this process after the injury?

3. You are employed?

What type of job do you have?

4. Have you always worked?

5. If no, when did you return to work?

6. Did you ever have need for financial aid?

7. How did you feel about receiving aid?



8. Do you think you will require any help in the future?

9. If yes, what type?

10. Have you had any especially helpful experiences in your contact with professionals or agencies?

\_\_\_\_\_ yes

\_\_\_\_\_ no

Would you tell me about them?

11. Have you had any especially negative unhelpful experiences?

12. Some people have told us that their religion played a part in adjusting to S C Injury, has this been true for you?

If yes, in what way?

13. Were there anything about \_\_\_\_\_'s adjustment which concerned you?



14. We speak about adjusting to disability, what does it mean to you?

15. Suppose that a person's overall adjustment to spinal cord injury could be shown on a ladder having ten rungs, with the tenth run representing the best possible adjustment and the first rung representing the worst possible. At what point on the ladder would you place yourself to indicate your overall adjustment to \_\_\_\_\_'s injury?

16. Where would you place \_\_\_\_\_ on the ladder of adjustment?

17. Can you think of any changes which could be made to improve \_\_\_\_\_'s life or adjustment?

\_\_\_\_\_ yes

\_\_\_\_\_ no

IF YES

17a. What kinds of changes?

|                                    |                  |
|------------------------------------|------------------|
| _____ change in housing layout     | _____ car or van |
| _____ medical attention            | _____ work       |
| _____ attendant                    | _____ quit work  |
| _____ better social life           |                  |
| _____ change geographic location   |                  |
| _____ change in living arrangement |                  |





18. Whom do you think \_\_\_\_\_ has more in common with; other disabled people or able bodied persons?

\_\_\_\_\_ able bodied

\_\_\_\_\_ disabled

19. Are there things which you enjoyed doing but have given up because of \_\_\_\_\_'s disability?

\_\_\_\_\_ yes

\_\_\_\_\_ no

IF YES

19a. What kinds of things?

\_\_\_\_\_ dancing

\_\_\_\_\_ sports

\_\_\_\_\_ going shopping

\_\_\_\_\_ movies

\_\_\_\_\_ working

\_\_\_\_\_ being by self

\_\_\_\_\_ getting out

20. How much time per day do you spend physically caring for \_\_\_\_\_?

21. What things do you do for him? NOTE: Does with regularity

\_\_\_\_\_ feeding

\_\_\_\_\_ urinary appliance care

\_\_\_\_\_ dressing

\_\_\_\_\_ bowel program

\_\_\_\_\_ position change in bed

\_\_\_\_\_ personal hygiene

\_\_\_\_\_ or chair

\_\_\_\_\_ other

\_\_\_\_\_ transfers

22. How do you feel doing these things?

\_\_\_\_\_ enjoy

\_\_\_\_\_ at times get annoyed

\_\_\_\_\_ do it because it has to be done



23. Which tasks are most difficult or unpleasant for you?

24. Does \_\_\_\_\_ have an attendant?

\_\_\_\_\_ yes

\_\_\_\_\_ no

IF NO

24a. Why not?

\_\_\_\_\_ not necessary

\_\_\_\_\_ can't afford one

\_\_\_\_\_ can't find one

\_\_\_\_\_ other

25. Have you thought about what would happen to \_\_\_\_\_ if you became unable to continue to care for him?

\_\_\_\_\_ yes

\_\_\_\_\_ no



APPENDIX E  
DYADIC ADJUSTMENT SCALE





Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

|                                                 | Always<br>Agree | Almost<br>Always<br>Agree | Occa-<br>sionally<br>Disagree | Fre-<br>quently<br>Disagree | Almost<br>Always<br>Disagree | Always<br>Disagree |
|-------------------------------------------------|-----------------|---------------------------|-------------------------------|-----------------------------|------------------------------|--------------------|
|                                                 | <u>5</u>        | <u>4</u>                  | <u>3</u>                      | <u>2</u>                    | <u>1</u>                     | <u>0</u>           |
| 1. Handling family finances                     | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 2. Matters of recreation                        | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 3. Religious matters                            | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 4. Demonstrations of affection                  | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 5. Friends                                      | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 6. Sex relations                                | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 7. Conventionality (correct or proper behavior) | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 8. Philosophy of life                           | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 9. Ways of dealing with parents or in-laws      | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 10. Aims, goals, and things believed important  | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 11. Amount of time spent together               | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 12. Making major decisions                      | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 13. Household tasks                             | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 14. Leisure time interests and activities       | _____           | _____                     | _____                         | _____                       | _____                        | _____              |
| 15. Career decisions                            | _____           | _____                     | _____                         | _____                       | _____                        | _____              |



|                                                                                                           | <u>All<br/>the time</u> | <u>Most of<br/>the time</u> | <u>More<br/>often<br/>than not</u> | <u>Occa-<br/>sionally</u> | <u>Rarely</u> | <u>Never</u> |
|-----------------------------------------------------------------------------------------------------------|-------------------------|-----------------------------|------------------------------------|---------------------------|---------------|--------------|
|                                                                                                           | <u>0</u>                | <u>1</u>                    | <u>2</u>                           | <u>3</u>                  | <u>4</u>      | <u>5</u>     |
| 6. How often do you discuss or have you considered divorce, separation, or terminating your relationship? | _____                   | _____                       | _____                              | _____                     | _____         | _____        |
| 7. How often do you or your mate leave the house after a fight?                                           | _____                   | _____                       | _____                              | _____                     | _____         | _____        |
| 8. In general, how often do you think that things between you and your partner are going well?            | _____                   | _____                       | _____                              | _____                     | _____         | _____        |
| 9. Do you confide in your mate?                                                                           | _____                   | _____                       | _____                              | _____                     | _____         | _____        |
| 10. Do you ever regret that you married?(or lived together)                                               | _____                   | _____                       | _____                              | _____                     | _____         | _____        |
| 11. How often do you and your partner quarrel?                                                            | _____                   | _____                       | _____                              | _____                     | _____         | _____        |
| 12. How often do you and your mate "get on each other's nerves?"                                          | _____                   | _____                       | _____                              | _____                     | _____         | _____        |

|                                                                | <u>Every Day</u>       | <u>Almost<br/>Every Day</u> | <u>Occa-<br/>sionally</u> | <u>Rarely</u>               | <u>Never</u>            |
|----------------------------------------------------------------|------------------------|-----------------------------|---------------------------|-----------------------------|-------------------------|
|                                                                | <u>4</u>               | <u>3</u>                    | <u>2</u>                  | <u>1</u>                    | <u>0</u>                |
| 23. Do you kiss your mate?                                     | _____                  | _____                       | _____                     | _____                       | _____                   |
|                                                                | <u>All of<br/>them</u> | <u>Most of<br/>them</u>     | <u>Some of<br/>them</u>   | <u>Very few<br/>of them</u> | <u>None of<br/>them</u> |
|                                                                | <u>4</u>               | <u>3</u>                    | <u>2</u>                  | <u>1</u>                    | <u>0</u>                |
| 24. Do you and your mate engage in outside interests together? | _____                  | _____                       | _____                     | _____                       | _____                   |

How often would you say the following events occur between you and your mate?



|                                          | Never    | Less than<br>once a<br>month | Once or<br>twice a<br>month | Once or<br>twice a<br>week | Once a<br>day | More<br>often |
|------------------------------------------|----------|------------------------------|-----------------------------|----------------------------|---------------|---------------|
|                                          | <u>0</u> | <u>1</u>                     | <u>2</u>                    | <u>3</u>                   | <u>4</u>      | <u>5</u>      |
| 25. Have a stimulating exchange of ideas | _____    | _____                        | _____                       | _____                      | _____         | _____         |
| 26. Laugh together                       | _____    | _____                        | _____                       | _____                      | _____         | _____         |
| 27. Calmly discuss something             | _____    | _____                        | _____                       | _____                      | _____         | _____         |
| 28. Work together on a project           | _____    | _____                        | _____                       | _____                      | _____         | _____         |

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no).

|           | <u>Yes</u> | <u>No</u> |
|-----------|------------|-----------|
|           | <u>0</u>   | <u>1</u>  |
| 29. _____ | _____      | _____     |
| 30. _____ | _____      | _____     |

Being too tired for sex.

Not showing love.

31. The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy", represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

| 0                    | 1                 | 2                   | 3     | 4             | 5                  | 6       |
|----------------------|-------------------|---------------------|-------|---------------|--------------------|---------|
| Extremely<br>Unhappy | Fairly<br>Unhappy | A Little<br>Unhappy | Happy | Very<br>Happy | Extremely<br>Happy | Perfect |

32. Which of the following statements best describes how you feel about the future of your relationship?

- 5 I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
- 4 I want very much for my relationship to succeed, and will do all I can to see that it does.
- 3 I want very much for my relationship to succeed, and will do my fair share to see that it does.
- 2 It would be nice if my relationship succeeded, but I can't do much more than I am doing now to help it succeed.
- 1 It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
- 0 My relationship can never succeed, and there is no more that I can do to keep the relationship going.



APPENDIX F  
GLOSSARY OF TERMS





GLOSSARY OF TERMS

|              |   |                                                                                                       |
|--------------|---|-------------------------------------------------------------------------------------------------------|
| catheter     | - | a tubular instrument for passage through body channels, chiefly for discharging fluids from a cavity. |
| cervical     | - | pertaining to the neck or the cervix                                                                  |
| coccygectomy | - | excision of the coccyx                                                                                |
| condom       | - | a rubber sheath to be worn over the penis in coitus                                                   |
| lumbar       | - | pertaining to the loins                                                                               |
| lumbosacral  | - | pertaining to the lumbar and sacral region, or to the lumbar vertebrae and sacrum                     |
| radius       | - | lateral and shorter bone of the forearm                                                               |
| reduction    | - | restoration of the normal relationship of parts, as in fracture, luxation or hernia                   |

















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